UNIVERSITY OF SOUTHAMPTON

## ABSTRACT

**FACULTY OF SOCIAL SCIENCE**

**PSYCHOLOGY**

**Master of Philosophy**

# DISCURSIVE ENVIRONMENTS IN HOSPICE DAY CARE

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Although there has been an increase in hospice day care in recent years, there has been little research, and little agreement as to the purpose of this aspect of care of the dying. The study aimed to identify the various understandings of hospice day care imbedded within the social setting.

An 'ethnographic' research design was used to enable the collection of both textual and contextual information in and about hospice day care. Participant observation amounting to 285.25 hours was carried out in three hospice day care units over a total period of ten months. Six nurses, 41 patients, and 36 volunteers were involved in the study. Twenty-nine audio-recordings of spontaneous conversation between participants were taken and documentary information was collected. In addition, semi-structured interviews were conducted with 11 patients, four nurses and eight volunteers. Data analysis was informed by the work of discourse theorists although material, as well as discursive features were considered important.

Four 'discursive environments' were identified reflecting the various ways that hospice day care can be construed. Day care as an 'outpatient clinic' is construed as a specialised unit for the monitoring and palliation of patients' symptoms. Alternatively, day care as a 'social club' is considered a place to meet people, make friends and have fun. As a 'care home' day care is understood to be about providing a warm, comfortable environment in which staff can give patients special care. Finally, as a 'rehabilitation unit' day care is considered to provide 'therapy' whereby patients are helped to enhance their creativity, independence and life satisfaction.

The inherent social relations of the 'discursive environments' differ markedly. In the 'outpatient clinic', nurses are viewed as 'specialists' doing the work of the clinic and patients are considered passive recipients or objects of care. In the 'social club' the formal roles 'nurse', 'patient', and 'volunteer' are secondary to the role of 'friend'. Patients are considered active as 'friend', 'entertainer' and/or 'audience'. In the 'care home' environment the staff give 'special' care. In receiving this special care, patients are passive, dependent and child-like. In contrast, in the 'rehabilitation unit', patients are in a position to give as well as receive and relationships are based on co-operation and reciprocity.

These analytic findings challenge the view of a unified hospice approach, offering four distinct, although in practice overlapping, models of care.

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# TRANSCRIPTION CONVENTIONS AND ABBREVIATIONS

In order to transcribe audio-recorded material, the ‘basic’ transcription conventions proposed by Parker (1992) were used. These are detailed in section 2.2.9. For ease of presentation in this thesis, the conventions employed for each extract have been further simplified. The conventions used are:

Rounded brackets ‘( )’ indicate that there are doubts about the accuracy of the material contained therein.

Square brackets ‘[ ]’, if empty, indicate that material has been omitted from the transcript. If the brackets contain material, the contents provide a clarifying explanation for the reader.

Abbreviations are often used within square brackets indicating the status or roles of individuals within the research setting. These are as follows:

| | |
|---|---|
| DCL | Day care leader (a qualified nurse who runs day care) |
| CA | Care assistant (an ‘unqualified’ nurse who supports the work of the day care leader) |
| PT | Patient |
| VOL | Volunteer |
| SN | Senior nurse (a qualified nurse who manages the hospice as a whole) |
| PHYSIO | Physiotherapist |
| OT | Occupational Therapist |

Throughout the field note and transcript extracts, individuals are referred to using the initial letter of their first name. To discriminate between individuals with the same initial letter, a second or even a third letter is used. Only the researcher knows the names and individuals associated with these initials. In the interview and conversation transcripts the initials ‘AL’ denote the researcher.

# 1. INTRODUCTION TO HOSPICE CARE

The majority of deaths in contemporary British society are often a prolonged process taking place over a considerable period of time (Walters, 1995). In the past death was more often a rapid event usually the consequence of infectious disease, but nowadays the majority of deaths are the result of chronic diseases, such as cancer. In 1931,13 per cent of deaths were due to cancer, but by 1992 the percentage of cancer deaths had increased to 25 per cent (The Health of the Nation Report, 1991). It is estimated that one in three people will develop cancer, and one in five will die from the disease (Nash, 1992). Between the years 1980 and 2000, it is predicted that the numbers of people dying from cancer will increase by 20 per cent in men, and 12 per cent in women (E.C.Workshop on Palliative Medicine, 1993). Cancer is therefore a relatively common condition; one that is destined to place increasing demands upon health care services. It is unsurprising then that the range and number of services provided to cater for people with terminal cancer has expanded over the last 20 years (Higginson, 1993a).

This chapter details hospice care in Britain today and is divided into four main sections. The first section describes hospice care for the dying; it's origins, evolution, and philosophy. The second section focuses on the hospice services available in Britain today, and funding issues, tracing changes from the beginnings of the hospice movement to current day. The third section outlines some of the major themes, or current issues in hospice care, and the final section of the chapter concerns day care, a setting for hospice care delivery which has undergone rapid expansion in recent years, and for which there has been very limited research.

## 1.1. HOSPICE CARE FOR THE DYING

The hospice care available today for people with terminal illness is the product of many years of evolution (Hockley 1997). Moreover, hospice care is continuing to adapt and develop in a changing socio-economic, political and even religious climate.

### 1.1.1. The origins of the 'hospice movement'

The term 'hospice' originally indicated "resting place for travellers or pilgrims" (Twycross, 1986). Dwellings such as these were usually run by monastic orders to obey commands set out in the Bible (Matthew 25:35,36). The first use of the term 'hospice' specifically in relation to dying people came in 1842 when Jeanne Garnier opened her first refuge for the dying in Lyon, France. Shortly after this in 1879 the Irish Sisters of Charity opened Our Lady's Hospice for the Dying in Dublin.

The modern hospice movement is said to have begun in the 1960s when St.Christopher's Hospice, set up by Dame Cicely Saunders, opened to provide in-patient and home care. Inspired by her work as a nurse in St Luke's Hospital in London, Saunders undertook her medical training and began work in St. Joseph's Hospice in 1958. Saunders introduced regular 'on demand' pain relief drugs and the collection of systematic medical and nursing notes. This then facilitated the production of lectures and papers, which in turn, allowed the funding for the development of St. Christopher's Hospice in London. There followed the generation of research into different aspects of care for the dying (eg. Hinton, 1963; Parkes, 1984; Twycross, 1984), and expansion of the services available. Although the hospice movement was founded largely upon the Christian religion, in modern times many hospice units are not directly affiliated to a specific religious denomination.

### 1.1.2. Hospice philosophy

Despite many in-patient facilities called hospices, it is acknowledged that the term "hospice" does not merely represent a building (Manning, 1984). According to Hayslip and Leon (1992), "hospice" is a concept of care for people who have terminal illnesses and their families, through the utilisation of an interdisciplinary team that develops an individualised plan of care. Moreover, "hospice" is a philosophy reflecting an attitude towards a particular type of care. Emphasis is placed on *care* rather than *cure*, and the family is treated as the unit of that care. Cicely Saunders promoted a holistic model of care, introducing the concept of "total pain". The aim of hospice care is to ease the patient's "total pain": his or her mental, spiritual and physical distress. Within hospice care the quality of life of the individual and his or her family is paramount. The main features of the hospice care, as set out in some of the main hospice texts, are:

- effective pain relief
- attention to psychosocial and spiritual needs
- teamwork
- rehabilitation
- open and honest communication
- care in a homely environment if not the patient's own home
- bereavement support

(Saunders and Sykes, 1993; Manning, 1984; Hayslip and Leon, 1992; Twycross, 1986)

Although there is some disparity as to the exact features or philosophy of hospice care, authors are in general agreement that hospice care is to enable the patient and his or her family to achieve an appropriate or 'good' death (McNamara *et al*, 1994). As the hospice movement has evolved, the medical establishment has become increasingly involved in hospice care for the dying.

### 1.1.3. Medicine and hospice care

The hospice movement gained impetus and prestige within the main health care system when in 1987 'palliative care' was recognised as a sub-speciality in medicine (Doyle 1993). According to Doyle (1993) palliative medicine is "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life." (p.253). The creation of academic chairs in palliative medicine together with the name change of the World Health Organisation Cancer Division to the 'Division of Cancer and Palliative Care' has further increased the standing of the speciality. In 1993 the European Community programme 'Europe Against Cancer', recommended that palliative medicine be included in the undergraduate and postgraduate curriculum of all doctors (E.C.Workshop on Palliative Medicine, 1993). Since 1988, the National Health Service (NHS) take-over of a proportion of the funding for Cancer Relief Macmillan fund services, has also served to acknowledge and bolster the growth of palliative medicine as a distinct speciality (Higginson, 1993b). Alongside this, the advance of medical technology has also brought benefits. For example, the introduction of battery operated syringe drivers has revolutionised symptom control, enabling specialists in palliative medicine to 'fine-tune' pain management to suit the individual (Higginson 1993a).

There has been some confusion centred on for whom palliative medicine is to be provided, and at what stage of illness it is appropriate to start. Although perhaps replacing the expression 'terminal care', authors and clinicians are quick to point out that *end-stage* care is only a part of palliative care (Thorpe, 1993; Higginson, 1993a). Strictly speaking, palliation or the alleviation of symptoms without cure could be available to most people with any disease that has symptoms that need to be controlled. Indeed, taking drugs to reduce headache and dry up over-productive nasal mucous membranes associated with a streaming cold, are both efforts to palliate, rather than to cure the underlying condition. Although rather extreme, this example outlines the problems associated with the term "palliative"; it refers not only to the dying.

Whilst acknowledging the importance and necessity of a palliative *approach* in most health related services, Doyle (1993) restricts palliative *medicine* for those who, everyone agrees, has 'active, progressive and far-advanced disease' (E.C.Workshop on Palliative Medicine, 1993). A WHO expert committee in 1990 argued that palliative and curative care are not mutually exclusive (WHO Report, 1990). According to the committee, palliative care should not be limited to the last weeks of life, but should be a gradually increasing component of care from diagnosis to death. It has been argued that the isolation and shock felt by people after having been diagnosed with cancer, and the trauma of having to inform relatives, warrants the involvement of palliative care from the beginning (Birchumshaw, 1993). Doyle (1993), however, asserts that a palliative approach, employing the principles of good palliation, is appropriate from diagnosis, but that referral to a palliative medicine specialist is only appropriate at a later stage.

In Britain, modern day hospice care services are the result of the recognition of palliative medicine as a medical speciality and the development of the hospice movement. Hospice care is now used synonymously with the term 'palliative care' defined as, 'the active, and total care of patients whose disease no longer responds to curative treatment, and for whom the goal must be the best quality of life for them and their families' (Directory of hospice and palliative care services, 1994 p.iii).

The World Health Organisation considers palliative care to have five main objectives in the care of the terminally ill (Johnston and Abrahams, 1995). The aims of palliative care are to:

- affirm life and regard dying as a normal process, neither hastening nor postponing death
- provide relief from pain and other distressing symptoms
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients live as actively as possible until death
- offer a support system to help the family cope during the patient's illness and their own bereavement.

Despite the recognition and acceptance of palliative care as the means by which we care for our dying in today's society, the integration of the hospice movement and palliative medicine, together with an increasing integration into mainstream health care, means that the modern hospice movement faces a number of challenges. These will be outlined in section 1.3.

# 1.2. SERVICE PROVISION AND FUNDING

## 1.2.1. Hospice services

### 1.2.1.1. In-patient units

In the last twenty years service priorities in hospice care services have changed. In response to the poor treatment of dying people in hospitals, the hospice movement in Britain initially expanded by increasing the number of in-patient units (Higginson 1993a).

In 1997 there were 223 in-patient units, providing a total of 3253 beds (Directory of hospice and palliative care services, 1997). Patients can be admitted as an in-patient for symptom assessment and control, respite, investigatory and medical interventions requiring monitoring, as well as terminal care. In-patient units are provided in a variety of locations. Many palliative care services provide in-patient beds in a suitably built or adapted building. These can be located within the grounds of a hospital or away from hospitals altogether. Some in-patient units are sited within hospital buildings themselves, occupying a ward or department.

### 1.2.1.2. Home care

In 1980 a report by the Working Group on Terminal Care recommended that further expansion of in-patient facilities was no longer required. Alternatively, the authors emphasised the need for an integrated system of care between primary care, hospital care and the hospice movement (Wilkes, 1980). A few years later a report by the Centre for Policy on Ageing also recommended that the development of home care services should take priority over further in-patient units (Taylor, 1983). Taylor (1983) argued that home-care is less expensive and makes care available to a greater number of people in the place they want it. It is perhaps not surprising then that the number of palliative home-care services began to increase.

Home care nurses (also known as ‘clinical nurse specialists’, ‘Macmillan nurses’, and ‘symptom control nurses’) are specially trained in cancer care to provide emotional support to patients and their carers as well as advise on pain and symptom control. They make regular home visits to their patients and in so doing work alongside general practitioners and primary health care teams in the community. There are now over 408 home care teams (Directory of hospice and palliative care services, 1997).

### 1.2.1.3. Day care

Alongside the endorsement of home-care, Taylor (1983) recommended that as one of a number of “less expensive but invaluable support services”, the provision of hospice day care needed to be developed. Consequently, since the publication of these reports, the number of day hospice services has also increased. Indeed, this area of palliative care is expanding more rapidly than other services (Higginson, 1993a). Since the opening of the first purpose built day hospice in 1976, the number of day care units has increased to 234 (Directory of hospice and palliative care services, 1997). Day care centres are located alongside in-patient facilities or independently away from hospice and hospital settings, although two thirds of Britain's day care facilities are attached to in-patient units. Usually managed by nurses, they provide physiotherapy, occupational therapy, hairdressing, chiropody, aromatherapy, creative and social activities for patients, as well as enabling respite for carers.

#### 1.2.1.4. Hospital Support Teams

Concurrent with the increase in home and day care services, hospice care has been drawn into hospital settings. As originally endorsed by the Wilkes report in 1980, emphasis is now being placed upon hospital support services. Hospital support services range from a team of doctors, nurses, social workers and chaplains, to a single support nurse. These professionals are responsible for giving advice, providing symptom control, pain relief and emotional support for patients and carers in the hospital setting. There are now 315 of these services (Directory of hospice and palliative care services, 1997).

### 1.2.2. Hospice funding

Historically, hospice services have mainly been provided by the voluntary sector. Of the 223 in-patient units open in 1997, 148 were classed as Voluntary Hospice Units funded entirely by registered charities. 11 units were Marie Curie Cancer Care Centres and eight were Sue Ryder Foundation Homes. Only 56 units received funding from the National Health Service (NHS), and these units also received funds from the Cancer Relief Macmillan Fund (Directory of hospice and palliative care services, 1997). The national charitable organisations, therefore, have had a major role in the development of the hospice movement. Although only a minor contributor at the beginning, the NHS has gradually increased the amount of funding available to hospices over the last decade, and there is now predominantly collaborative funding.

In the late 1980s, concerns were raised as to whether the hospice movement could continue to cover the revenue costs of the increased number of palliative care facilities that were coming into existence (Taylor, 1983). The increased salary bill resulting from nurse regrading in the NHS was an added burden upon the hospice movement, and led to demands for more funding from the Government (Clark, 1991). In 1987, a Department of Health circular (DoH, 1987) requested all district health authorities (DHAs) examine the provision of palliative care services in their area. Central Government then gave additional financial resources of £20 million per annum to each DHA specifically to support palliative care in the voluntary sector (Clark, 1991). At this time Government ministers advocated a 'partnership' between the NHS and the hospice movement, whereby funding provided by the two sectors was matched 'pound for pound'. Central funding then doubled for the year 1990-1991, and in 1992 the Government gave £37.2 million to DHAs for palliative care services, and offered a further £5 million specifically for paediatric hospice facilities (Higginson, 1993b).

There was some controversy over exactly how central funding was used by the DHAs. Help the Hospices, an umbrella organisation concerned with the development and support of hospice services, claimed that some DHAs: inappropriately allocated monies to the NHS rather than the voluntary sector; used the new monies to reduce support from their main stream funds; and used the monies to fund new rather than established services (Help the Hospices, Health Services working group, 1990). However, the findings of a survey of 22 DHAs countered these negative claims (*National Association for Health Authorities and Trusts*, 1990). The authors reported that DHAs were financing *over* 50 per cent of the costs incurred by hospices, more than they were required by Government to give. In the calculation, the authors had included the non-cash DHA support, such as free consultations with NHS doctors for hospice patients (James and Field, 1992), free laundry services, and the donation of unused hospital land for siting a facility (Clark 1991).

Alongside the changes in external funding, James and Field (1992) argue that competition amongst charities for individual donations has increased and become more professional. Nowadays the hospice movement employs staff and takes on volunteers specifically to raise funds.

Now that specialist palliative care services have both public and private sector funding, the hospice movement in Britain is not immune to the major changes that have been taking place in the NHS. Since the 1989 NHS and Community Care Act, service provision has been subject to contracts between health departments. Service providers compete to win contracts from purchasers. As purchasers, DHAs can now seek to contract for the most cost-effective, and high standard of palliative care from a variety of different providers. As a result, in the future hospices may have to compete with NHS or private hospitals offering their own terminal care (the NHS and Community Care Bill, briefing paper, 1990). Whilst it is claimed that the purchaser-provider ethos of health care nowadays is counter to the holistic principles of hospice care (James and Field, 1992), other authors consider that there "is no *prima facie* reason why hospice care cannot adapt to the new context" (Clark, 1991). Clark (1991) suggests that in the future hospices can either become (or remain) totally independent financially from the NHS or take their place within the purchaser-provider market. Future financing and resource management is but one issue debated within the modern hospice movement.

## 1.3. CURRENT ISSUES FOR THE HOSPICE MOVEMENT

Within the last decade a number of concerns have been raised about the present state of the hospice movement and its future development. These concerns are set out in the following section and relate to the medicalisation of death, the institutionalisation of the hospice approach, education and research, the 'spiritual calling' to hospice work, who should receive hospice care and the optimal form of hospice.

### 1.3.1. Increasing medical focus

At the outset, the hospice movement arose to challenge the dominant medical model of terminal care by providing an alternative, or more 'humane', death for people with advanced cancer. As the hospice movement becomes increasingly aligned with mainstream health services, it is argued that it may compromise one of the hospice movement's primary aims; to care for people as human beings rather than objects of disease. Although some authors consider the benefits of medical technology in the care of the dying (e.g. Higginson 1993a), others have argued that the increased use of medical technology makes the hospice movement's mission paradoxical. For example, Siebold (1992) claimed that medical technology; the devices, instruments and procedures it invents, serve to de-humanise the care of the dying thereby undermining the ideals of the hospice approach. Other authors have argued that the authority of the medical model within the health care system and society as a whole, as well as the use of technology, sets up a "medical technical imperative" (McNamara *et al* 1994 p.1505). McNamara *et al* (1994) warn that the modern hospice movement must work to remain aligned to the principles of caring rather than curing. James and Field (1992) caution against "reprofessionalisation" whereby the traditional bio-medical emphasis on physical symptoms and professional dominance reassert themselves (p.1370). Bradshaw (1996) takes this last point further arguing that to work in a hospice now requires considerable training and qualifications in the medical speciality of 'palliative care'. Bradshaw (1996) goes on to claim that the term ‘palliative care’, takes a step away from the original ethos of hospice terminal care by removing any connotations of death. Although the medicalisation of hospice is a concern raised by many authors, attempts are being made to redress the balance within the care of the dying. For example, Corner and Dunlop (1997) suggest that the hospice movement can move beyond biomedicine by ‘reframing’ care so that the individual and his/her own understanding is placed at the core of therapeutic intervention.

### 1.3.2. Institutionalisation of the hospice approach

Some authors claim that in addition to its medicalisation, the hospice approach is becoming rationalised, routinised and bureaucratised as it becomes integrated into mainstream health care. Although James and Field (1992) claim that it is a ‘natural’ progression as the ‘charismatic’ beginnings of the hospice movements subside (James and Field, 1992), concern remains about the institutionalisation of the hospice approach. There are concerns that the hospice movement, instead of being open and flexible in it’s ideas and methods of care for the dying, may become rigid and formal in delivering care. For example it is argued that the ideas surrounding the ‘good death’ aim of hospice care, have become more prescriptive so that patients who do not adhere to this ideal are problematised (McNamara et al 1994). Within the purchaser–provider culture following the reform of mainstream health care, the hospice movement has not only to adapt to an alteration in the system of financing, but also to provide evidence of its cost effectiveness and efficiency. Clinical evaluation and audit is therefore necessary if hospices are to compete successfully with other health care services to win contracts for care. As well as competing for funding within the health service market place, hospices are now increasingly required to compete for funding from the voluntary sector, which, it is argued, has resulted in the professionalisation of fund raising activities (James and Field 1992). There is the risk that the increasingly heavy burdens of administration brought about by the integration of the hospice movement into the mainstream health system may detract from the three elements of the hospice: care, education and research.

### 1.3.3. An over-emphasis on education and research

Since it’s inception, the hospice movement has carried out research, in an attempt to define optimal forms of care, and education, to disseminate the hospice approach, alongside the actual care of the dying. Recently, however, concerns have been raised about an imbalance between the three aspects of the hospice movement. James and Field (1992) assert that there is “a danger of the ‘tail’ of education wagging the ‘dog’ of hospice care” (p.1372), and Bradshaw (1996) warns that an increased focus on education and research means that hospices have become “prestigious ‘goldfish bowls’ attracting people from far and wide to look inside” (p.415). James and Field (1992) go on to argue that there is pressure from the mainstream health system to conduct evaluations and audit; measurements of quality and/or cost-effectiveness, of hospice care. The definition and measurement of the qualities of hospice care such as ‘empathy’, ‘effective communication’, ‘feelings’, ‘satisfaction’, and ‘well-being’ is contentious and difficult. James and Field (1992) propose that hospice researchers may divert their attentions from these ‘soft’ factors to more easily measured ‘hard’ indicators of treatment resulting in the primacy of physical care over other forms of care. McNamara *et al* (1994) focus on another ‘soft’ concept associated with the hospice movement. They claim that the continued search by researchers and clinicians for the definitive ‘good death’ introduces intellectual structures that are imposed by those that care for the dying rather than the dying themselves.

Whilst it is important for those in the hospice movement to be aware of these issues and to make every endeavour to maintain a balance between care, education and research, it is necessary to bear in mind that hospice was originally set up as a tripartite system (Clark 1991). Care, education and research have been the three facets of the hospice movement since it’s beginnings.

### 1.3.4. Lack of ‘spiritual calling’

In their sociological analysis, James and Field (1992) forward the view that the success of the hospice movement is a result of having: 1) a leader (Dame Cicely Saunders), 2) a narrow focus (cancer care), 3) an oppositional stance (to that of mainstream care of the dying as it was), and 4) the ‘spiritual calling’. The authors argued that for many of the founding members of the hospice movement, a sense of religious (mainly Christian) vocation drew them to the care of the dying. James and Field propose that staff now enter the hospice movement for employment or a career rather than a spiritual calling, and warn that this may have detrimental effects. Bradshaw (1996) goes on to argue that it is the ‘spiritual calling’ which holds the key to the future development and changes in hospice care. He examines the secularisation of the hospice movement, arguing that following the spiritual calling of the founders of the hospice movement the religious ethos has become marginalized. Bradshaw (1996) claims that without attention to its religious basis the hospice movement is at risk of merely being a ‘therapeutic technique’ for professional empowerment.

## 1.3.5. Who is hospice care for?

As pointed out by James and Field (1992), the 'narrow focus' of the hospice movement upon people dying with malignant disease has contributed towards the success of the hospice approach. However, criticism has been levelled at hospices for being exclusive; available to only a very privileged few (Seale 1991b). Thus there have been calls for the broadening of the hospice umbrella to make care available to people suffering from other terminal illnesses. Palliative care is now seen to be for those with life-threatening disease but who are not imminently dying (Higginson 1997). This includes people with Multiple Sclerosis, AIDS, Motor Neurone Disease, as well as individuals with circulatory and/or respiratory disease. Not all hospices, however, may be able to cater for such diverse needs, and questions are being raised about whether the model of care developed for people with cancer can be adapted for those with non-malignant disease (Higginson 1993a).

## 1.3.6. Types of hospice service.

As is described in section 1.2, hospice care is delivered in a number of ways: in-patient care, home care, day care and hospital support teams. In the past, expansion primarily involved the development of in-patient facilities. This was a cause for concern amongst some who have advised against the unplanned proliferation of such units (NAHA 1987, Department of Health 1990, 1992). The influential Wilkes report (1980) called for the co-ordination between the primary care sector, the hospital sector and the hospice movement in the delivery of care. Home care, day care and hospital support services are now in expansion, although it remains unclear as to whether hospice services should endeavour to supplant, supplement of support mainstream health care.

According to Payne (1998) some hospice services are organised to 'supplant', or replace, existing services. They offer a "total package" (p.1501) including in-patient facilities, home care, day care, and family support alongside full medical and nursing care. 'Supplementary' hospice services, however, provide specialist palliative care resources or facilities, although the existing services are seen to be the principle agencies for delivering palliative care. Hospices designed to provide day care and/or bereavement support, for example, could be classified as supplementary, adding to the services and facilities available through primary health care teams and local hospitals. The third form of hospice service, those designed to 'support' mainstream health care services, provide the resources such as equipment skills and knowledge, that enable patients and families to cope better with terminal illness. Payne (1998) described volunteer hospices in New Zealand which provide individuals with a community support package including frozen meals, visitors and transport. Hospital support teams are also considered to be a 'support' form of hospice care because they provide individual consultancy and have an educative function for other health professionals. Payne argues that if equity of provision is considered to be the key goal for the future, 'support' services such as these may be the most viable option. Clark and Neale (1994) argue that in the future a community-based approach, emphasising the role of primary health care teams, should be the highest priority in the development of hospice services. In this view, specialist home care nurses and day care facilities should be developed to support the work of the district nurses and general practitioners in the care of the dying.

## 1.4. DAY CARE

Day care is available in many sectors of the British health and social system. An on-line search for published work relating to 'day care' mainly yields items concerning facilities for children, the mentally ill, the elderly, and the elderly mentally ill. It could be argued that hospice day care resembles day care for the elderly more than services for the other client groups. Day care for the elderly and hospice day care have similar roles in some ways (Edwards *et al*, 1997). Both services are multi-functional, serving a number of medical, social, and support purposes, and both may draw upon a similar client group. The increasingly high proportion of terminally ill people over the age of 75 (Field and James, 1993), means that in terms of age, hospice day care and day care for the elderly serve a similar population. Similarly, both services are available to people with primarily a physical disease or disability. Geriatric Day Hospitals, providing day care for older people, and have been in existence for considerably longer than hospice day centres. The evolution and workings of elderly day care may be informative as to the possible issues that are to be faced in hospice day care.

### 1.4.1. Day Care for the Elderly

The original concept of day care for the elderly evolved from day services for psychiatric patients in Russia. Elderly day care first became established in the UK in 1954 (Cosin, 1954) and in 1958 the first purpose built geriatric day hospital (GDH) was opened in Oxford. At this time, the GDH had a mix of medical and social aims in order to maintain elderly infirm people at home (Vetter, 1989). There followed a period of expansion and integration of the GDH into general NHS elderly care services, and in the 1960s the functional emphasis of the GDH became rehabilitation, active treatment and assessment. (Nolan, 1987). This purposive change, Nolan (1987) contends, coincided with the evolution of geriatric medicine as a distinct speciality. Given this, it is unsurprising that in the report entitled "Geriatric Day Hospitals", the Royal College of Physicians and the British Geriatric Society (1994) explicitly state that GDH are now said to follow a 'medical' model staffed by medical, paramedical and nursing personnel. The former 'social' functions of the GDH, the report contends, have become attributed to 'day care centres' run by voluntary organisations or the social services (Royal College of Physicians, 1994). Rather than focusing on illness and disability, the objectives of 'day care centres' are said to provide recreation and social activities for patients and a period of respite for carers (Royal College of Physicians, 1994). These units do not usually have input from therapists, nurses or medical practitioners and provide a mid-day meal and transport to and from home.

According to the Geriatric Day Hospital report the overall aim of the modern GDH remains the same; to enable elderly people to continue living at home. However, the care priorities of these units now concern 'rehabilitation' and 'physical maintenance' through treatment. Rehabilitation, in which recovery or improvement is anticipated, is a relatively short-term, finite process. In contrast, maintenance is a long-term process requiring prolonged and regular attendance to maintain previous gains in physical function. Nursing and medical procedures are provided for people who are attending a GDH although, it is argued, attendance should not be solely for this purpose (Royal College of Physicians, 1994). Similarly, for patients who have access to day care centres, social and respite care are no longer reasons for attending a GDH, although there may be incidental benefits of attendance.

Research evaluating the effectiveness of Geriatric Day Care has been inconsistent and even contradictory. This ambiguity is considered to be a result of the different outcome measures employed (service, patient and carer outcomes) and the different forms of care (short- and long-term care) that is provided. In the current health care system of 'purchasers' and 'providers', it is essential for day care providers to produce evidence of their quality and (cost)effectiveness in order to compete successfully for contracts. To this end the Royal College of Physicians provided guidelines for good practice and a clinical audit scheme for Geriatric Day Hospitals to unify their research and ensure that results are comparable.

The division of elderly day care into 'medical' and 'social' care has not gone without criticism. Nolan (1987), favouring the original all encompassing role of the GDH, called for nurses to re-negotiate the role of the day hospital with medical colleagues so that the social and psychological implications of disability are recognised. Pahl (1989) undertook a study comparing the provision of day care for the elderly (social services, voluntary and NHS) in Kent and found that the clientele using the different services were remarkably similar in terms of mental impairment, illness and disability. Because the different forms of day care served a very similar population, it is argued that there is no need for elderly day care to be either 'medical' or 'social' in function, and that a 'holistic' day care service may be more appropriate.

Pahl (1989) found that the elderly people in the study valued social contact more than any other aspect of day care. For this reason, the author goes on to suggest that day care services "should not be seen as 'hospitals' and 'assessment units', where social interaction is a pleasant by-product...but rather as social clubs where medical and nursing care, therapy and so on are available as necessary and where 'patients' and 'clients' can become more like partners..."(p.10). However, the guidelines for good practice provided by the Royal College of Physicians (1994) explicitly promote a separatist approach to day care favouring a medical model for Geriatric Day Hospitals. It seems that despite the suggestions that day care for the elderly should become less medically oriented, the authority of the medical institutions will maintain the *status quo*.

### 1.4.2. Hospice day care

Many different names are applied to the centres that provide day care for people with terminal illness. Some consider 'day hospice' to be more appropriate than 'day care' or 'day centre', arguing that these latter terms are more often linked with other client groups (Nevitt and Eisenhaur, 1995). For the purpose of this thesis, however, 'hospice day care', as favoured by the National Association of Palliative and Hospice Day Care Leaders, will be used.

#### 1.4.2.1. Hospice day care provision

The first purpose-built hospice day care unit began at St. Luke's Hospice, Sheffield in 1975. In 1997 the number of day care units had expanded exponentially to *234* (Directory of hospice and palliative care services, 1997). The number of places for patients in each unit varies considerably. It has been estimated that nationally there are 11,000 day care places, with the number of places per unit per week ranging from six to 125 (Copp *et al*,1998). Copp *et al* (1998) report that 131 units (60% of total number of units in the United Kingdom) provide 6881 places a week. An earlier analysis of figures provided by 144 units (Eve *et al*, 1997) found there were 1428 day care places per day with a mean of 12.6 places daily per unit. It has been recommended that there should be one day care place per 10,000 of the population, the optimal capacity being 20 places per unit per day (Scottish Partnerships Agency, 1995).

The majority of units are open three to five days a week, with Monday to Thursday being the most popular opening days (Copp *et al*, 1998). Attendance rates of day care have been difficult to ascertain. Eve *et al* (1997) report a mean daily attendance rate of 68% whereas the data published by Copp *et al* (1998) yield an attendance rate of only 60%. The majority of people attending hospice day care are diagnosed with advanced cancer. Although many day care units are open to people with non-malignant disease including HIV/AIDS, few have been exposed to treating these patients (Copp *et al*, 1998). Only very few people younger than forty years and over eighty years attend hospice day care, the majority are aged between 61 and 80 years.

The majority of day care units are funded by charitable organisations, and are linked to other palliative care services. Copp *et al* (1998) report that 84 (64%) of the 131 units they surveyed are funded independently, whereas 24 (19%) are funded by the NHS and 21 (16%) receive funding from both sources. Twenty-four (18%) of the day care units are attached to home care teams, 47 (36%) are connected to in-patient units, 45 (34%) are attached to both home and in-patient care. 15 units (11%) are not directly connected to other palliative care services.

Hospice day care is provided in a variety of settings; some units are purpose-built whilst others are in converted houses. Some day care units are sited alongside, or within other palliative care services such as in-patient units, and/or within hospital grounds. Other day care units are sited in buildings away from other palliative care and health related services. In some rural areas 'satellite' day centres meet at a different venue each day of the week (Nevitt and Eisenhaur, 1995).

### 1.4.2.2. Management, aims and services of hospice day care

Although no special training or qualification is required to enable health professionals to work in hospice day care, some professional recognition is afforded to members of hospice staff who manage day care facilities by the National Association for Hospice and Palliative Day Care Leaders. Established in 1993, this organisation holds an annual conference and produces newsletters for day care staff. In most cases, hospice day care is headed by a nurse of grade E or above (Copp *et al*, 1998). The majority of units have access to a doctor and have a range of other workers including volunteers, chaplains, complementary therapists, physiotherapists, social workers, occupational therapists, chiropodists and dieticians (Copp *et al*, 1998)

The broad aims of hospice day care include the maintenance or improvement of clients' quality of life, the provision of holistic care by a multidisciplinary team (Spencer, 1998), an opportunity for rehabilitation (Stevens, 1996), continuity of care, and helping patients to continue living at home for as long as possible (Thorpe, 1993). As well as enabling patients to remain at home longer and for them to become familiar with in-patient units before it should become necessary, hospice day care aims to provide a day out for patients and a day off for carers (Corr and Corr, 1992).

The services provided in day care include, practical nursing care and psycho-social support (Spencer, 1998; Copp *et al*, 1998) medical assessment, consultation, prescription and clinical interventions (Copp *et al*, 1998; Edwards *et al*, 1997; Sharma *et al*, 1993), socialisation and diversional activities (Thompson, 1990; Seely 1990; Stevens, 1996), rehabilitation (Hockley, 1993), complementary therapies (Copp *et al*, 1998; Eve *et al*, 1997) respite and support for carers before death and bereavement support after death (Spencer,1998; Copp *et al*, 1998).

As well as providing a means of introduction to hospice in-patient facilities (Olson,1989; Corr and Corr, 1992) hospice day care is thought to enable patients to remain at home for longer (Fisher, 1991; Hockley, 1977). This has considerable cost implications for the palliative care service, implications which have not gone without acknowledgement. A decade after the Wilkes (1980) report stating that the advantages of hospice day care should be examined, Fisher (1991) concluded that day care is an economical way of supervising and giving care. It was estimated that five purpose-built day care units could be built for the price of one in-patient facility, arguing that this also applies to on-going revenue expenses. Although palliative home-care costs and the costs payable by general practitioners and domicillary nursing services need to be considered to estimate the true cost of maintaining patients at home (Higginson, 1993a), there is a general assumption that day care is cost-effective and efficient form of palliative care (e.g. Taylor, 1983). There are now calls for research into the cost-effectiveness and quality of care delivery in hospice units (Higginson, 1993a; Spencer, 1998).

### 1.4.2.3. A review of research in hospice day care

Studies have focused on palliative care in a variety of settings: hospitals, hospice in-patient units, and in the home. Despite it being a rapidly expanding area of palliative care (Eve *et al*, 1997), it is interesting that very little research has turned to hospice day care. Even in a recent review article concerning palliative care in different settings, there was no mention of hospice day care (O'Henley *et a*l, 1997). In the introductory passages of a major palliative care text, the author acknowledges that although day care is important as an aid to home based care, it is to be omitted from the book (Penson and Fisher, 1991). It seems that because it is viewed simply as an adjunct to in-patient and home-care services, hospice day care has been largely ignored and research to consider its form, process and effectiveness is virtually non-existent.

Papers or chapters concerning day care mainly consist of general outlines of day care services (Corr and Corr, 1983; McDaid, 1995; Nevitt and Eisenhaur, 1995; Newbury (1991), descriptions of a single hospice day care (Gibson, 1993; Thompson, 1990), or details about how to set up a day care service (Seely, 1990; Corr and Corr, 1992)

To date there has been one book, and one review article published about hospice day care (Fisher, 1996; Spencer, 1998). Whilst focusing entirely on day care, the book (Fisher, 1996) offers a prescriptive text for the provision of palliative day care, and as such contributes little to the research base surrounding the topic. The review paper (Spencer, 1998), although acknowledging that there is a dearth of research into hospice day care, is critical of qualitative descriptive studies and unsurprisingly calls for research to evaluate the cost-effectiveness and quality of the service. On occasion, research papers concerned with palliative care make a mention of day care, but only very rarely has research focused upon day care itself.

The first research paper focusing on day care was published in 1978 (Wilkes *et al*, 1978), describing the first "day hospital" (at St. Luke's Hospice in Sheffield) designed for people with advanced cancer and chronic disease. Using audit data the article describes the first twenty-six months of the unit, aiming to highlight the issues in the provision a day care service. The authors also conducted a postal survey of bereaved relatives and patients who attended the unit. The day hospital was not found to effect the length of stay in the in-patient unit or the rate of discharge home. Patients and relatives rated the service highly: 90 per cent thought that the support provided was of great importance to both patient and family; and over two thirds of the patients were said to have benefited from improved control of symptoms.

Although most of the subsequent publications concerned with hospice day care refer to this one paper and cite it as evidence of the benefits of the service, the research may not be representative of hospice day care in the late 1990s, having been conducted some twenty years ago. In addition, the 50 per cent response rate to the postal questionnaire also casts some doubt over the representativeness of the findings. Nevertheless, the authors assertions that day care is relatively cost effective and an "easy way of starting to meet the needs of dying patients and their families" (p.1056), have been highly influential.

The charity 'Help the Hospices' commissioned and published a study specifically to evaluate hospice day care (Faulkner *et al*, 1993). Faulkner and her colleagues conducted an observational study in twelve British day hospices. Constructed from the findings of preliminary visits, researchers used an evaluative proforma to guide their assessment of each day care unit. Prior to the researchers' visits, staff at each day care unit completed a questionnaire regarding information about attendance patterns, numbers and types of staff, the objectives of day care, transportation of patients, and staff training. Researchers aimed to identify good practice and common problems, and to review the educational objectives for staff. Good practice was linked to: 1) giving support, friendship and care; 2) providing social interaction and stimulation; 3) facilitating personal growth and confidence through creative and therapeutic activities; 4) giving respite to carers; and 5) offering clinical surveillance and medical care. Problems in day care were largely to do with the constraints of accommodation and resources, the multiple duties of the nurse, a lack of objectives and contractual arrangements for admission and discharge. With regard to the educational needs of the staff, the study recommended an ongoing training programme accessing local education resources for both health professionals and volunteers.

Although the study was useful in highlighting the multi-faceted nature of hospice day care, there are some methodological and conceptual problems with the research. Firstly the period of observation in each unit was extremely limited. Visits were made to each day care unit on only one occasion and for a period of between only 1½ to 3½ hours. This is an extremely limited amount of time in which all aspects of day care were to be assessed. It is unlikely that any one day care unit could be explored to any depth within this time. A second limitation of the study relates to the type of observation conducted. Although the observation was 'structured' in that observations were made according to an assessment proforma, the report does not describe the observation process. The manner in which observations are collected may influence the research participants in what they say and do.

A third problem with the study lies with the use of a predetermined schema to assess each day care unit. Although constructed from preliminary visits to day care units, the pre-visit questionnaire limited the responses participants' could make regarding the objectives of day care. Participants were required to prioritise four objectives (clinical surveillance, carer respite, social interaction and creative activities), and were therefore faced with making a forced choice between a very limited number of possible day care objectives. It could be argued that the limited number of objectives provided in the questionnaire was restrictive and indicative of the researchers' underlying bias towards these components of day care.

Similarly, a fourth limitation is associated with the assumptions underlying the research. The study aimed to evaluate day care in that the authors wanted to identify 'good' practice. There have been no systematic evaluations of hospice day care and no national day care standards exist, which means that it is difficult to establish what is 'good' and what is 'not good' practice. However, this is exactly what the research has attempted to do. The assumptions on which the researchers' judgements were based are not explicit, although hints can be found in the closed questions regarding day care objectives as described above, and the criticism of day care units who did not prioritise 'clinical surveillance' and/or encouraged patients to be "jolly" (p.20). Paradoxically, whilst negatively evaluating the view these units took, the researchers asserted that the relative merits of the different approaches to day care should be comparatively evaluated, and national standards devised.

A fifth problem with the study is based on the concentration upon the views and actions of the health professional. Patient input appears to be minimal. A member of staff in each unit completed the pre-visit questionnaire, and the observations were focused mainly on the behaviour and perceptions of the staff. Patients' perceptions were relegated to a small section late in the report findings. At no point is it clear whether the patients were asked about what the objectives of day care are, or should be. Given that the literature proposes that hospice day care aims to enhance patients (and carers) quality of life, it would seem imperative to fully acknowledge the views of the service users in order to adequately evaluate the service.

A sixth limitation of the research relates to the 'informal' nature of the research and its presentation. The form of analyses used to explore the data collected within the observation periods is not articulated and no data-based evidence is given to substantiate the assertions that are made. These means, once again, that the researchers underlying assumptions regarding hospice day care cannot be separated from the information gathered during observation.

The study conducted by Faulkner *et al* (1993) provides a superficial account of hospice day care, which cannot be considered value-free. What the study repeatedly shows, and possibly what caused much of the confusion, is the variation in the understanding of 'hospice day care'. Like the 'quality of life' it is purported to enhance, hospice day care is multi-dimensional and understood in many different ways. It means different things to different people at different times.

Sharma *et al* (1993) conducted a small study in a hospice day care unit in Kent, focusing on patients' expectations and need for medical care. Initially, a questionnaire was administered to 26 patients. The findings reported that 43 per cent of the patients considered access to a doctor to be one of the reasons for coming to day care, 96 percent found access to a doctor beneficial, and 77 per cent valued advice on their medication. A further study was conducted over a 12-week period whereby the doctor kept a record of his or her attendance at the centre, the time spent on various activities, and the medical problems encountered. The paper reports the average length of time the doctor spent in various activities in day care, together with a list of the medical problems presented by the patients, and the consequences of consultations (e.g. blood test investigations).

The need to be selective in presenting data is understandable, but it is questionable as to whether the responses provided by the patients to the questionnaire are adequately reflected in the paper presented. For example, the paper reports that 43 per cent of the patients included medical care as a reason for initially coming to day care. What other reasons persuaded these patients to come to day care, and for what reasons did the majority of patients (57%), who did not cite ‘access to a doctor’, come to day care? It could be argued that the authors were over-selective in their data reporting to make the findings appear to support their own position in favour of medical input in hospice day care.

With regard to the second study, it had already become customary for the doctor to attend day care every day so that medical problems could be assessed and treatments prescribed. It is unsurprising, therefore, that the doctor spent on average 40 minutes a day in the unit, and encountered, investigated and treated a number of medical problems. Considering the pre-existing medical service provided in this day care, one of the reasons some of the patients will have been referred will be for clinical surveillance and medical input. It is only to be expected that medical input will be required. The major finding of this study is, therefore, a self-fulfilling prophecy. This is not to question the role of medical input into hospice day care, but rather to question the bias in the report.

In a similar vein to Sharma *et al* (1993), Edwards *et al* (1997) examined the characteristics, expectations and needs of patients in order to determine an appropriate level of medical input into their hospice day care. Over an eight month period, new patients were asked to: 1) identify and rate their physical problems in terms of severity; and 2) state how they expected day care to help them. The person who referred the patient was also contacted and asked what they expected day care to provide for the patient. The patients were reviewed weekly for the first month and fortnightly thereafter.

The study found that the two most frequently cited reasons for referral were social interaction and carer respite, although monitoring of patients condition, introduction to the hospice, psychological support, and doctor’s opinion/symptom control were also reasons given for referral. Although symptom control was the reason for referral least stated, the initial assessment revealed inadequate control of symptoms with many patients suffering moderate to severe pain, nausea and vomiting, constipation, dyspnoea and general weakness. The day care unit was successful in reducing the severity of, or eliminating all the symptoms except dyspnoea and general weakness. The unit was also successful in alleviating anxiety and raising low mood in the majority of patients who presented with these problems. The authors conclude that the inadequate control of physical symptoms revealed at the initial assessment, and the improvements made through medical intervention, warrant future medical assessment and follow up of patients in day care.

Edward *et al* (1997) successfully demonstrate the need for medical input in hospice day care, however, there are a number of criticisms that can be levelled at their research. Like the research conducted by Wilkes *et al* (1978) and Sharma *et al* (1993), the study took place in a single day care unit. Authors are already critical of this research approach (Spencer, 1998) and the generalisability of the findings is also open to question. In addition all three of these pieces of research were conducted by hospice workers themselves. Studies carried out by 'insiders' may be biased in that the researchers have a vested interest in achieving a favourable outcome or one that conforms to their expectations.

Copp *et al* (1998) conducted a telephone survey of 131 day care units in the UK. Day care leaders were questioned about the nature of service provision, management and organisational issues, and the nature of common problems and care issues of day care patients. Many of the findings have already been articulated in this chapter. However, the authors also focus attention upon the models of care that may be adopted in hospice day care: 'medical' and/or 'social'. Their findings indicate that the range of medical and psychological services provided by the day care units in the study appear to be related to the source of funding. NHS and combined NHS and independently funded day centres were reported to provide a greater range of medical and other services. Parallels could be drawn here between day care for the elderly and hospice day care. Units with NHS input may be more medically oriented, whereas centres funded by other means adopt a more 'social' model. However, Copp *et al* (1998) caution against such generalisations, stating that first it is "important to explore whether such models exist, and if so, to elicit the different working practices and cultures of these two, or indeed, more models and their impact on patient outcomes." (p.168).

The assumption that these two distinct models exist in hospice day care is evident in the literature. For example, Gibson (1993) states that according to the social model, day care gives people time out from their illness, companionship, support and diversional activities. In contrast, the medical model of day care provides an "intense service" where all physical, social and spiritual needs are addressed (Gibson, 1993: p.263). It could be argued that the papers presented by Sharma *et al* (1993) and Edwards *et al* (1997) are a consequence of tension between the two models of care. The authors, concerned about the marginalisation of medicine in day care, are striving to demonstrate the need for medical in-put in these units. Tensions are also evident between the medical and social models of day care in the research conducted by Faulkner et al (1993). As described above, the authors are critical of the units that do not adhere to a medical model. It seems that the social and medical models of care are often portrayed as in opposition. This is contrary to the holistic ethos of the hospice approach.

Hospice day care has been the most rapidly expanding area of palliative care in recent years. Despite this and acknowledgements of it's importance as an adjunct to and bridge between home-care and in-patient care, there has been very little research exploring hospice day care. There are no national guidelines for hospice day care and the statistics referring to it are incomplete and inaccurate (Eve *et al*, 1997). Little is known about day care, what it offers, how it works (and *if* it works), or simply what goes on in these units. With the new market based health care system operating in the NHS, it is imperative that palliative care services gather information regarding the various facilities that are offered (Eve *et al*, 1997). Whilst there has been some success in relation to in-patient and home-care, hospice day care remains an unknown entity. As Copp *et al* (1998) conclude, in-depth studies are necessary in order to "gain an insight and understanding into the complexities and functions of different models of day care…and their impact on management, organisation and patient care requirements."(p.169). The aim of the current research is to explore the form and process of hospice day care: what it is, and what goes on.

# 2. METHODOLOGY, PROCEDURE AND ANALYSIS.

This chapter is divided into three main sections. The first section details the methodological assumptions upon which the research is based, the second section focuses on the procedural aspects of data collection, and the third section describes the analytic process undertaken. Because of the participatory mode of research in which the researcher herself can be considered the main 'research instrument', this chapter is written in the first person.

## 2.1. METHODOLOGY

The analytic approach and emphasis taken in the research as a whole was informed and guided by the events and findings of the preliminary study outlined in section 2.2.1. The language used in and about day care served an important function in the organisation and understanding of the day care setting. This finding led me to place analytic emphasis upon discourse, the verbal and written language used in and about day care. The analytic goal was therefore to identify the discursive practices giving rise to the various understandings (or constructions) of 'hospice day care'.

### 2.1.1. Social constructionism

The discourse analytic approach has accompanied what has been described as the social constructionist movement in modern psychology (Gergen, 1985). According to Gergen (1985) the social constructionist orientation is "concerned with explicating processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live. It attempts to articulate common forms of understanding as they [now] exist" (p.266). Stemming from the ideas articulated in Wittgenstein's (1963) 'Philosophical Investigations', the social constructionist movement has brought to the fore the role of linguistic convention, or language use, in the construction of meaning. In so doing, the social constructionist movement has emphasised the multiplicity of understandings that are generated across time and culture. In contrast to the single physical reality many empiricists seek to understand and map, social constructionists concentrate upon the many social realities people construct and inhabit.

The aim of discourse analysis is therefore to articulate the many and varied understandings of the world people manufacture in the way they talk and write. Although discourse analysts have this common goal, they attempt to achieve it in a variety of ways.

Authors have written about the different forms of analysis (eg. Fairclough, 1992), but for the purposes of this thesis 'discourse analysis' is here sub-divided into 'micro-' and 'macro-' analysis.

Micro-analysis tends to focus on the *act* of speech. By this it is meant that analysts pay attention to the minutiae of the action of speaking: pauses, timings, in breaths, voice volume and overlaps, to name but a few. Micro analysts therefore attempt to articulate the informal rules of language use.

In contrast to micro-analysis, macro-analysis focuses more upon word usage, looking at the different words and metaphors adopted in 'texts' in order to articulate the understandings, discourses or interpretive repertories that people draw upon when talking or writing about their social world. Although it is understood that how people talk is important, it is the latter 'macro-' form of analysis that is adopted in this study. The analysis was broadly informed by the work of Parker (1992).

### 2.1.2. Identifying discourses

Parker (1992) articulated a 'system of statements' that are a prerequisite to a discourse analysis. These reflect the assumptions underlying discourse analysis, and as such represent the 'mind set' of the discourse analyst. These assumptions are set out below.

1) '*A discourse is a coherent system of meanings*', whereby the "metaphors, analogies and pictures discourses paint of a reality can be distilled into statements about that reality" (p.10). Parker went on to say that the statements in a discourse can be grouped, and become coherent, according to their reference to a particular topic.

2) The second underpinning assumption for discourse analysts refers to where discourses can be found. Parker proposed that '*a discourse is realised in texts*'. 'Text' commonly refers to verbal and written language but Parker takes it further, arguing that "non-verbal behaviour, Braille, Morse code, semaphore, runes, advertisements, fashions systems, stained glass, architecture, tarot cards and bus tickets" (p.7) are also forms of text. It is the translation of such a text into written or spoken form that renders discourse visible.

3) According to Parker, a discourse '*reflects on it's own way of speaking*' in that it is possible to find instances where the terms used are commented upon. At these times the discourse reflects upon its own way of speaking. For example, as an author of a text, a research participant may be conscious of his/her language use, acknowledging and discussing the terms he/she has written or uttered. Similarly, Parker advocated that analysts reflect upon

the terms they use to describe discourses, being aware that they involve moral evaluation and political choice.

4) Parker also asserted that *'a discourse refers to other discourses'*. By this he meant that in order to articulate one discourse, there must be at least one other discourse with which the original contrasts. Analysis is therefore facilitated by identifying contradictions between different ways of describing something. Parker, however, argued that different discourses may draw upon the same metaphors and so analysis also needs to focus on the interrelationship between discourses.

5) In the statement, *'a discourse is about objects'*, Parker referred to "two layers of objectification" (p.8). Firstly, a *discourse* is considered to be about objects (although many of the objects that discourse refers to do not exist in a realm outside discourse) and secondly, a *discourse analysis* is about discourses as objects. At the first level, the objects referred to in the discourse are the focus of study and at the second level, the discourses themselves are objectified, becoming the object of study.

6) Parker proposed that *'discourse contains subjects'*. This means that discourses invite certain perceptions of ourselves and others. This depends on how the discourse addresses us as the audience/readers, the rights we have to speak within that discourse and the position we can take within the discourse. Consequently, discourses can treat us as, say, 'patients', 'family members', 'customers', or any other subject form.

7) A seventh assumption forwarded by Parker asserts that *'a discourse is historically located'*: "discourses are located in time in history, for the objects they refer to are objects constituted in the past by the discourse or related discourses. A discourse refers to past references to those objects."(p.16).

Parker (1992) proposed that these seven statements, or theoretical assumptions, are necessary and sufficient for an analysis leading to the identification of discourses. However, Parker's ideas and those of other discourse theorists may be interpreted in an increasingly narrow or blinkered manner which gives rise to what could be called 'limitations' of discourse analysis. The 'solutions' to the 'limitations' of discourse analysis articulated below provide the methodological rationale for the research presented in this thesis.

## 2.1.3. 'Limitations' of discourse analysis

### 2.1.3.1. Limitation 1

Discourse analysis could be said to disregard or even to actively side step 'context'. Analysis often involves the detailed examination of a piece of a transcript isolated from the environment in which the text was created. In focusing solely upon what a research participant is saying, many discourse analysts fail to consider communicative ingredients such as body posture, facial expression, and gesture. In addition an analysis of discourse often disregards the physical surroundings of text production; the architecture, the seating arrangements, peoples' dress and such like, which may have a part to play in people's understandings of their social world(s). The lack of interest in 'context' is probably the consequence of a broader 'problem' within discourse analysis.

#### 2.1.3.2. Limitation 2

Discourse analysis often neglects the materiality of our world, overlooking the material aspects of the world(s) we inhabit. In their zeal to take the discursive turn, many analysts actively disregard material phenomena in favour of discursive features in order to explain our social world. It could be argued that the mind - body dichotomy which has plagued social psychologists for years is being replaced by a split between 'material' and 'discursive' phenomena. In carrying out their analysis upon isolated transcripts, discourse analysts serve to depict the social world as separate from the physical world. Contextual features, like those outlined in the previous section, may be disregarded simply because of their 'material' basis.

**Solution:** It is hard to deny that there is a physical reality and yet this is perhaps what discourse analysts are attempting to do, or at least it is a corollary of their efforts. Discourse analysts need to explicitly take the material features of the research setting into account when conducting an analysis of discourse. Parker (1992) advocated the inclusion of some material elements in discourse research. In his second statement relating his idea of a text, Parker incorporated physical phenomena in his list of what can be regarded as text, and by way of example discussed the discourses existing within the text of an electronic game, a material object.

Although Parker (1992) considered the seven criteria outlined above as necessary and sufficient for marking out particular discourses, he also drew attention to aspects of discourse upon which research should focus. One of these 'auxiliary criteria' related to the material - discursive dichotomy. In his statement, "the employment of a discourse is often a practice which reproduces the material basis of the institution" (p.17), Parker argued that a discourse (and the institution supported by it) is a product not only of what people *say*, but also what they *do*. For example, the medical discourse exists in a variety of texts such as medical journals, books, research reports and doctor consultations, but is also to be found in certain practices such as feeling an abdomen or giving an injection. Parker drew upon the work of Foucault (1972), who proposed that discourses and practices should be treated as if they are the same thing. It is argued that practices, or what people do, should be given the same status as a text. Parker (1992) therefore suggested that discourse research should encompass material phenomena rather than deem it irrelevant.

Other authors advocating a discursive approach have also emphasised the need to include material phenomena within analyses. Miller (1994) proposed that the non-discursive, material aspects of settings such as the size of social settings' memberships, typical sites, and the material resources available to setting members may be analysed as "the conditions of possibility for discourses" (p.302). There remains, however, a problematical schism between that classed as ‘material’ and that categorised as ‘discursive’. Again drawing upon the work of Foucault, Prior (1997) provided an alternative way of thinking by referring to 'text' and 'context', considering both relevant in discursive analyses. Prior suggested that analysts should consider texts as a research topic, focusing on how they are created, and in order to do this it is necessary to look at the context of the texts. Prior gave an example of how text and context can be researched. Referring to the work of Aries (1981:1985), the author described how varied phenomena such as cemetery layout, the arrangement of human bodies, the style and content of paintings, icons and other texts “intertwined and interconnected to express coherent discourses on death” (p.77). The analytical approach proposed by both Miller (1994), and Prior (1997) demonstrated that discursive analyses can encompass both discursive and material elements, so that contextual details play some part in the overall research findings. The notions of 'text' and 'context' may be a more profitable way of conceptualising phenomena to be included in an analysis of discourse.

#### 2.1.3.3. Limitation 3

Discourse analysis focuses inwards. This ‘limitation’ of discourse analysis may also be a consequence of the discursive turn away from the material foundations of reality. Discourse analysis is often employed to deconstruct personal attributes, qualities and/or conditions. Discourse analysis therefore tends to focus *inwards* at the ‘person’, looking at how aspects of a person’s character, mind, personality, health, body or beliefs are manufactured through language. Discourse analysis rarely looks *outwards* to the environment, to the social world itself and the people within it. Discourse analysis, therefore, is rarely used in research where the social setting is the object of study

**Solution:** The study of 'social settings' is usually considered the domain of ethnography rather than discourse analysis. Some authors, however, are attempting to build bridges between discourse analysis and ethnography to examine social settings. Spencer (1994) referred to a "continuum of analytic foci"(p.267) ranging from 'ethnographic' studies attempting to describe social contexts from the participants perspective through observation, fieldnotes and interviews, to studies of the structure and content of naturally occurring conversation. Spencer called for the incorporation of elements of a discursive approach into ethnography and vice versa. The ethnographic element of such research should be concerned with the social and organisational contexts in which discourse takes place, informing the collection and analysis of that discourse data. The discourse-based elements of this type of research should be concerned with how the social and organisational processes of the social world under study provide a context for, and are routinely accomplished or negotiated by, setting members.

Miller's (1994) 'ethnography of institutional discourse' combines the ethnographic and discourse analytic approaches to provide a way of empirically examining the ways that discourse is reflexively related to socially organized contexts. The aim of such research is to identify and articulate 'institutional discourses' using field-based or ethnographic methods. Institutional discourses "consist of the fundamental assumptions, concerns, and vocabularies of settings and their usual ways of interacting with one another. *Institutional discourses are shared and standardized frameworks for anticipating, acting in, and reflecting on social settings and interactions.* They allow and constrain setting members to organise their interactions as instances of standardized types of social relationships and produce conditions for responding to issues in predictable ways. Institutional discourses are also accountability frameworks to which setting members attend in organizing their behavior in social settings and assessing and responding to others' behavior" (p.283) [original italics]. As well as advocating the inclusion of both discursive and material (or contextual) data, this definition demonstrates how Miller's research approach allows the social setting to become the object of study. In the sense introduced above, ethnography of institutional discourse looks *outwards*.

### 2.1.4. Ethnography, discourse analysis and hospice day care

The research in this thesis has been informed by Parker's (1992) criteria for distinguishing discourses, Prior's (1997) notions of text and context, and Miller's (1994) approach towards 'ethnography of institutional discourse'. Analysis is turned outward to focus on a social setting rather than inwards upon the participants therein. Parker (1992) proposed a working definition of a discourse as “a system of statements which constructs an object”. In the present research, the discursive ‘object’ is ‘hospice day care’. Data collection is of an ‘ethnographic’ design to enable the accumulation of both textual and contextual information in and about hospice day care. This involves participant observation, interviewing, conversational audio-taping and the gathering of documents. Data analysis draws out the various understandings of hospice day care that are imbedded within the social setting.

## 2.2. PROCEDURE

The study took place in three consecutive day care units described in section three. Reference to these sites as site A, B and C reflects the order in which they were studied. Although the analysis presented in the chapters four to seven is based on the amalgamation of data collected at all three day care sites, the initial period of research in site A was considered a preliminary study and played a major role in the shaping of subsequent research in sites B and C. For this reason an outline will first be made of the preliminary study before attention is turned to the research procedures adopted.

### 2.2.1. The preliminary study

The preliminary study took place in site A over a period of seven weeks, June to August 1995. The purpose of this initial study was twofold: 1) to develop and practice an observational technique appropriate to the study setting; and 2) to develop and refine the research focus for the main study.

#### 2.2.1.1. Observational technique

Having no prior experience of observation it was imperative for me to actively spend time learning and developing the skills necessary for this method of data collection. This meant that I was to find out and practice the specific observational techniques that not only suited the purpose of the study and the setting/participants, but also the pragmatic limitations of using myself as a research instrument. I needed to find out the optimal length of time for each observation period, the times of day or events that were to be observed, where to observe, how much to participate in the events of the setting, and when and how to write field notes.

#### 2.2.1.1.1. Length of observation

I varied my time of arrival and departure, the events observed, my placement within the day care rooms and with whom I spent my time. It was found that the minimum satisfactory observation episode was two hours. This allowed sufficient time for me to settle in, and for the event of my arrival to become less prominent. The maximum length of daily observation was found to be four hours. If observation continued for any longer than this, my ability to recall events diminished. In addition, it was found that the writing of field notes took at least as long as the time spent on observation and so for pragmatic reasons the maximum length of observation was limited to four hours. Despite this, at times I had to be flexible and extend the length of time spent observing. This included the outings away from the hospice and days when the participants requested me to stay for celebratory events.

#### 2.2.1.1.2. When and where to observe

In order to gain an appreciation of the events of day care it was decided that observation would take place at varying times of day. Initially the nurses were concerned to know at what times I planned to be in day care. This meant that I had to let the nurses know in advance when exactly I would be attending the unit. After the first week, however, the nurses became less concerned about when I was to be in day care and no longer required me to let them know in advance. This enabled me to come and go more freely, varying the times as required.

I spent most of my time in the rooms used most frequently by the participants. This meant that most observation took place in the sitting room and conservatory, although some time was spent in the kitchen and therapy room. The 'open plan' nature of the main day care area facilitated observation, permitting me to see and hear events in areas further away. Although the patients characteristically sat in particular chairs, I was careful to sit in different seats and areas of the room at each observation period.

#### 2.2.1.1.3. Researcher participation

I initially intended to observe the events of day care without actually becoming involved. This form of 'fly on the wall' observation was found to be un-workable in the day care setting. Despite my attempts to be in the background looking on, I was brought into the action of day care by the participants. The patients at first interrogated me, and then put me to good use fetching, carrying, sorting, moving, and arranging objects and people. The volunteers spent considerable time talking to me about their lives and what brought them into hospice voluntary work, and the nurses repeatedly pointed things out to me, and drew me into general conversations. It became apparent that full participation was essential in order to build the trust necessary for the participants to accept me.

#### 2.2.1.1.4. The 'researcher' role

Observation was at all times overt. All participants were informed of the research and I was formally entitled a 'research student'. I attempted to present myself as a 'neutral' party interested in learning about day care and how to conduct research. It was anticipated that my identification as a 'nurse' or 'psychologist' might set up role expectations and/or alter participants' behaviour. I was careful, therefore, not to position myself as a 'nurse', 'volunteer', or 'psychologist' by introducing myself as a 'research student', and spending most of my time with the patients. Despite attempts to conceal my background, my qualification as a 'nurse' and my status as a 'psychology student' were made public by the day care leader, and during the course of the intense questioning I received from the patients. Careful explanation was required to ensure that participants understood I was not there to provide nursing care, and to reassure them that I was not "reading their minds". Because my 'nurse' and 'psychologist' status were problematic, it was decided that in future research I again would not inform participants of my background 'up front', but I would answer direct questions honestly. It became apparent that in order to gain trust and acceptance into the setting I must also be open to the participants, and willing to answer their personal questions.

#### 2.2.1.1.5. Note-taking and field notes

Overt note writing in the study setting was considered inappropriate because it would draw attention to me and make participants feel self-conscious thereby disrupting the natural events of day care. Although no notes were written in front of the participants, on occasion I left the area under observation to record key events, times and quotes. For this purpose I kept a small notebook and pen in a pocket, and 'went to the lavatory' at frequent intervals. These brief notes were designed to assist recall when I came to write field notes in full, away from the hospice site, as soon as possible after the period of observation. The writing of field notes was found to be very time consuming as described in section 2.2.1.1.1. Field notes were initially structured into 'observations' and 'reflection and interpretation'. These categorisations were found to hinder rather than assist recall of events and because of the participatory nature of the study, I could not easily separate myself: my feelings, thoughts and ideas, from the events in day care. In addition, the 'interpretation' heading was considered redundant because the mere writing of field notes and the accounts of events therein can all be described as a form of interpretation (Reissman, 1993). Consequently, field notes came to amalgamate both observation and reflection describing the events that occurred in chronological order.

### 2.2.2. Research focus

The initial broad focus of the research concerned the nature of communication about death, dying and illness between patients and carers. At this stage of the research, hospice day care was merely considered a context in which these issues could be explored. Once the preliminary study began, however, it became apparent that little was known or understood about hospice day care *in situ*. The variable and conflicting understandings and expectations of the service created problems for staff and patients.

Alongside this finding, the role of talk amongst day care participants became paramount. Patients generally chose simply to talk with others whilst in day care rather than 'do' anything. This talk was highly 'social' in nature, with much jocularity and teasing. This talk style was predominant even when talking about what could be called the serious issues of life and death. These findings are reported elsewhere (Langley-Evans and Payne, 1997).

Considering these two developments, it was decided that subsequent research would continue to focus on talk, but exploration would turn to centre on the function and use of language in the construction of 'hospice day care'. In procedural terms this meant that as well as recording observations in field notes, the audio recording of 'talk', both in natural conversation and in interviews was a data collection priority.

### 2.2.3. Access

Before research began in each site, I attended meetings with key health professionals (the gatekeepers) and obtained Research Ethics Committee approval. In site A, a meeting was held with the members of the multi-disciplinary team so that I could present my research proposal and ask permission of staff members. In site B, I met with the clinical nurse manager who gave her permission for the research to go ahead. The clinical nurse manager did not consider it necessary to seek the permission of the other health professionals (including the day care leader), however I did attend a multi-disciplinary team meeting to present plans for the study.

In site C, I attended a meeting with the clinical nurse manager and the day care leader to seek permission and discuss plans. There followed a preparatory meeting with the day care leader a few weeks before observation began in the day centre.

The three hospice sites were in the province of three separate Health Commission districts. This meant that research proposals were submitted to three Health Commission Research Ethics Committees. Some difficulties were experienced accounting for the use of qualitative methods of enquiry, the need to talk with 'dying' people and the issue of informed consent. These issues are known to be problematic for research ethics committees and are considered by some authors to be a consequence of a lack of knowledge about research methods and a paternalistic attitude towards patients (Cartwright and Seale, 1990; Wolcott, 1994). However, the areas of concern for the ethics committees were acknowledged, and the research approach used adhered to the guidelines for qualitative research in palliative care proposed by Wilkie (1997).

### 2.2.4. Entry

Having gained access to each site by way of ethics committee approval and permission from key hospice staff, it was then necessary for me to enter and settle into each setting. In each site I was introduced to the participants as a 'research student' looking at hospice day care and learning how to do research.

In sites A and C, the day care leader informed the patients in advance of the study, and introduced me to everybody. Before the study the site C day care leader also gave each patient a letter about the study (as required by the ethics committee), and discussed it's content one-to-one to allay any fears. In site B however, patients were not given any prior warning of my attendance, and I introduced myself when I initially arrived. I was careful in all sites to introduce myself individually to the patients, even if the day care leader had already introduced me.

The settling in period in each site differed according to the role(s) I was expected to perform. In site A, as described in section 2.2.1.1.2. patients saw me as an object of interest and then as a resource person. The nurses initially identified with my nursing qualification expecting me to go to the staff room for lunch, putting my name down as a 'member of staff' on a proforma, and permitting me to see the patients notes because I am a nurse.

In site B, the patients did not ask many questions, seeming to passively accept my presence. On occasion the nurses positioned me as a nurse, using me as a resource for information and assistance on nursing matters. In order to avoid this role assigned to me, I often feigned ignorance of medico-nursing issues.

In site C, the patients rapidly accepted my presence, many of them simply saying "Oh you're the one that [day care leader] has been telling us about". Although patients asked me questions, they were more to do with being sociable than finding out my personal details. The 'student researcher' role appeared to be accepted by most participants. The care assistant, however, appeared nervous in my company, always justifying his actions and explaining himself at great length. I was under the impression that the care assistant considered the research to be evaluative; making judgements about what was 'good' and 'bad' in day care. Many attempts were made to reassure him. Despite this, my presence in site C appeared to make little impact on the unit. It is possible that I was simply becoming more practised at entering study settings, but it is considered that the actions of the day care leader prior to and during the study, assisted greatly. The day care leader did not assign me to any role other than 'research student', and treated me as an interested participant.

Settling in to each study setting also involved the development of trusting relationships and participation in the activities of day care as described in section 2.2.1.1.4. It is perhaps a mark of my involvement that on leaving each setting for the final time, tea parties were organised and the day care leader gave a 'goodbye speech'. In sites B and C, I received gifts and cards signed by all the day care participants. In all instances I was told I would be missed.

## 2.2.5. Consent

It was important that patients were informed that a study involving them was taking place, and for their permission to be sought. This notion of 'informed consent' was not only a requirement of all the research ethical committees, but was also essential to enable me to develop a trusting relationship with the participants.

All participants were given information leaflets (see appendix 1) detailing aspects of the research (the research objective, how it was to be achieved, how long the study would take, what would happen to the information gained) and assuring participants of confidentiality, anonymity and their right to withdraw from the study. I also talked to participants individually and gave them at least a week to consider their participation, and raise and ask questions.

Following this, written consent was required from all day care participants (see appendix 2). Although in principle this is an essential element of conducting research, the notion of written consent is problematic in observational research. The formal layout and wording of the consent form (as required by the ethical committees) sets up the expectation that participants in the study are to be 'done to', or are to 'give something' to the researcher. This is based on the assumptions of quantitative research whereby measurements are taken from participants by researchers. In this case, however, participants in day care were simply being asked for permission to allow me to 'be there'. Consent forms implied that I was looking for people to participate in a study, whereas I was looking to the people in day care to allow me to participate.[1] As such the consent forms served to unnecessarily confuse and trouble participants. Despite this, written consent for the observational study was gained from all day care participants.

In sites B and C information leaflets concerning the audio-taping of conversations and interviews were given to participants at least a week before these aspects of the research began. In site B written informed consent was then sought for each of these activities. However, because this disrupted the on-going conversation (to be taped), and caused confusion for the interlocutors, separate written consent for this research activity was not sought in site C. Here, participants were asked to give verbal consent for conversational taping and interviews. Only one patient, in site C, refused to take part in the taped conversations, and to ensure that this in no way altered his involvement in day care, recordings were not taken in his presence. Because he was blind, I also took great care to inform the patient of my presence each day by greeting him and telling him where I was going to be.

In addition to written informed consent, the ethics committees required me to notify each patient's general practitioner of his/her involvement in the study. Consequently, letters were sent to all the patients' general practitioners.

### 2.2.6. Observation

Observation took place over a total period of ten months. In addition to the time spent for the preliminary study (seven weeks), four months were spent in each of sites B and C (January to April, and July to October 1996 respectively). A total of 285.25 hours of observation took place. 44.75 hours were spent in site A over seven weeks, 86.5 hours were spent in site B and 154 in site C, each over a period of four months. Each observational episode lasted from two to five and a half hours.

Observation primarily took place in the rooms in which most of the participants were situated. In site A, this was the sitting room and conservatory, in site B it was the day care sitting room and the main hospice sitting room, and in site C most observation took place in the sitting room and therapy room. These are relatively 'public' spaces open to all day care

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[1] In this thesis the term 'participant' is used to refer to all those who take part in *day care*, not just the research.

participants most of the time. Observation also took place in less public spaces such as the 'quiet room' in site C when relaxation sessions and 'private' discussions were held.

As found during the preliminary study in site A, participation on my part was required in sites B and C. Patients, nurses and volunteers continually drew me into activities and conversations, although once a trusting relationship had been established I was able at times to stand back and watch events without actually taking part. I took part in and observed art and crafts, physiotherapy exercises, relaxation sessions, briefings, meal times and went on day care outings.

Brief notes were taken, and field notes were written as described in section 2.2.1.1.5. In addition to the textual notes for each observational episode in sites B and C, I documented the seating arrangement of the key rooms, and the places where participants sat on room plans (see appendix 3).

### 2.2.7. Documents and conversations

The focus of the research is upon the way in which talk constructs 'hospice day care'. Although comprised of written rather than spoken language, documents such as nursing notes, memoranda, posters, newsletters and leaflets were collected to supplement field notes. Details from patients' nursing notes were also taken for administrative and descriptive purposes.

During the third month of study in sites B and C a compact audio-tape recorder was used to capture naturally occurring conversations amongst day care participants. The audio recording was overt, whereby all participants were aware that a recording was being taken and prior consent was obtained. Recordings were 30 to 90 minutes long depending on the length of the tape and the movement of participants away from the recorder. Eleven recordings were taken in site B, and eighteen in site C. In site B the recorder was left running on a table or convenient surface in view of all participants. In site C seven recordings were made whilst the recorder was carried by a 'host'. The day care leader, three patients and a volunteer were 'hosts' at different times. The tape recorder was carried by the 'host' in a bag made to hold small syringe driver machines for the continuous subcutaneous delivery of drugs. For both sites the majority of recordings took place in the main day care sitting room although recordings were also taken in the bathroom, therapy room and quiet room. Recordings were taken whilst a patient had a bath, during group physiotherapy, art and craft sessions, relaxation sessions, briefing sessions and a multi-disciplinary team meeting, as well as during periods of general conversation.

The quality of most conversational recordings was poor. The very nature of the communication was found to prevent comprehension of the recordings. Most conversations involved talk between a group of people speaking loudly and interrupting one another. Talk often 'split' so that there were parallel conversations that then joined and divided further. This means that many of the recordings had excessive levels of 'background' noise including laughter. Recordings of team meetings, briefings, relaxation sessions and patient bathing were relatively good quality. Although the bathing recording only involved two participants, the other recordings involved talk amongst groups. The formal structure of the meetings and briefings as well as the 'turn-taking' in relaxation sessions meant that participants generally talked one at a time whilst the others listened. It is therefore not 'group talk' *per se* that precludes adequate conversational recording rather it is the nature or style of the communication therein.

### 2.2.8. Interviews

Interviews were conducted in sites B and C in the final month of study. In site B, five patients, two nurses and three volunteers were interviewed, and in site C, six patients, two nurses, and five volunteers took part. No one, who was asked, declined to be interviewed, although some difficulties were experienced arranging times and days when participants were able and free to take part. Consequently participants were selected mainly on their availability, although in each site the nurses (the day care leader and care assistant) were considered a priority. Patient interviewees were all relatively longstanding day care participants because it was considered insensitive to interview new patients who were still settling in. One volunteer in site C was specifically selected because she had only just begun to attend day care.

Although attempts were made to ensure that the interviews were conducted in rooms familiar to the participants, this was not always possible. In site B interviews took place in the treatment room and a closed in-patient ward area, and in site C, the quiet room, a 'relatives' room and a closed ward area on the in-patient unit were used. All interviews were conducted in private with only myself and the interviewee present. All interviews were audio-tape recorded and lasted between twenty minutes and one and a half hours. Although the majority of interviews took considerably less time, the longest interview was with a care assistant. The length of this particular interview was mainly due to the interview style used.

Interviews were semi-structured covering a number of themes. To put interviewees at their ease and to reduce the power inequalities in the researcher - participant relationship a 'conversational approach' was taken as advocated by Potter and Wetherall (1987). The interview was introduced to the interviewees as a "chat" or "informal discussion", and the order of themes covered was left largely to the interviewee and the conversational 'flow'. I attempted to place questions where they fitted into the conversation rather than according to a predetermined schedule, although an interview checklist was kept at hand (see appendix 4). In addition to the conversational style of the interview, I made every attempt to put the interviewee at ease by providing drinks, comfy chairs, and adopting an 'open' body posture.

The themes covered in interviews with patients centred on:

1) the hospice (contact with, perceptions of, meanings attributed to the hospice as a whole);
2) day care (reasons for attending, what it offers, aspects enjoyed and not enjoyed, being and talking with other patients) and;
3) experience of illness (how and when illness began, what doctors have said, feelings about diagnosis and prognosis, treatments and future expectations).

The themes covered in interviews with nurses were:

1) the hospice (perceptions of, philosophy and aims);
2) day care (name, aims, similarities and differences, advantages and disadvantages, patient referral, selection and recruitment) and:
3) patient insight (meaning, policies, talking with patients, related difficulties).

The interviews with volunteers covered two main themes:

1) voluntary work in the hospice (contact, reasons for volunteering, training, aspects liked and disliked, coping with illness and death) and;
2) day care (name, aims, advantages and disadvantages).

Nurses and volunteers were also asked to give some personal details such as age, marital status, occupation, hospice experience and qualifications.

## 2.2.9. Transcription

Owing to the poor quality of many of the conversational recordings, transcription was not possible. Written summaries were made of these recordings detailing, where possible, the content and tone of the talk. The better quality conversational recordings and the interviews were transcribed in full according to the transcription conventions highlighted by Parker (1992 p.124). These are:

1) when there are doubts about the accuracy of material round brackets are used (like this);
2) when material has been omitted from the transcript, it is signalled by a pair of empty square brackets, thus [ ];
3) when the author clarifies something the explanation is put in square brackets like so [to help the reader]; and
4) when there are noises, words of assent, and so on, these are put inside slashes, like this /yes/.

These conventions are simple compared to the conventions commonly used by conversation analysts. 'Basic' transcription was employed for a number of reasons. Firstly, the analytic emphasis in this thesis is upon 'macro' language content rather than grammatical form and structure. Secondly, more detailed transcription is considered to involve an element of interpretation (Parker, 1992), and thirdly, the computer software used to assist data analysis can not accept the complex code markings required for more detailed transcription. Examples of interview and conversation transcripts can be seen in appendix 5.

## 2.3. ANALYSIS

Once interviews had been transcribed, field notes written and nursing notes copied into a computer word processing package, all the material was then transferred to the "Ethnograph" a computer software package to assist qualitative analysis. Line numbered print outs were obtained and the process of analysis began. The analytic process ran concurrent with and beyond data collection and started with the repeated thorough reading of all field notes, transcripts, documents and conversation summaries.

### 2.3.1. Coding

A process of coding began whereby texts were divided up into smaller, more manageable chunks and coded according to their superficial content. This data coding phase is considered a stage in the process of discourse analysis proposed by Potter and Wetherall (1987). The code words used to identify chunks evolved during the coding process and were consequently subject to constant revision. This means that some initial codes were eventually discarded, replaced, subdivided or amalgamated into a final coding system. The coding process enabled me to become completely familiarised with the data. Only after the completion of data collection was the coding system finalised and entered into the

"Ethnograph" software package. The package was, in this instance, used simply as a storage and retrieval system for texts according to the entered codes. As a filing system, the "Ethnograph" facilitated the management of a large body of textual data.

Code words were used to describe the content and the general meanings conveyed in the textual chunks (see appendix 6 for a list of code words and definitions). For example, the code 'DCETHOS' is an abbreviation for "day care ethos" which was applied to any chunk of text that portrayed a general feeling or milieu in day care. 'DCCON', an abbreviation for "day care context" referred to any chunk of text that made reference to the physicality of the day care environment. The code words employed were not mutually exclusive. This meant that any one piece of text could be allocated to any number of codes, depending on interpreted meaning of the content. Chunks of text therefore tied particular codes together, and this helped to begin to form inter-connected frameworks or linkages within the data as a whole (an example of a coded data file is in appendix 7).

In an attempt to 'validate' the codings, a person uninvolved in the research read chunks of text relating to a number of codes. The assistant was 'blind' in that he was unaware of the coding system or specific code words used for the groupings of the textual chunks. Having read the chunks allotted to one code word, the assistant briefly described why he considered the grouping was made to see if there was general agreement with the codings applied by myself. The process was then repeated for other codes.

The method of coding described so far was 'superficial' in that at no point was attention given to the way(s) meaning was generated in the textual chunks. As such the analysis could be described as 'common sense'. Warnings have been made about analysis that only describes and confirms 'common sense' (Potter et al 1990), but at this point in the analytic process this was all that was required. The meaningful content of the chunks was taken at face value simply to allow me to accommodate and file away all the data. Having been allocated to one or a number of codes or categories, however, it was then important to move on to a 'deeper' level of analysis to consider *how* meaning was conveyed in the chunks of text.

### 2.3.2. Discursive analysis

Analysis here is guided and informed by the "criteria for distinguishing discourses" proposed by Parker (1992) as described section 2.1.2. These criteria provide a theoretical framework from which textual data can be viewed and the analysis described below is guided by the assumptions therein.

Once the coding system was applied to all the data, print outs of chunks of text relating to each code were obtained and examined closely. Analysis primarily focused on the terms and metaphors that were used by participants (including the researcher) when talking in and about day care, although the non-verbal actions of the participants (what they did, when, where and with whom) and the physical surroundings were also explored. Whilst all pieces of text subsumed under a particular code were initially grouped because they had something in common, analysis now turned to look at the differences, inconsistencies and contradictions that inhered in and between the textual chunks. See appendix 8 for an example of the analysis. The analytic process drew out the multiple meanings implicit within the texts, highlighting the tensions and conflicts between these understandings. This led to the identification of four conflicting understandings, or 'discursive environments' of day care. The researcher then went back to read original un-coded portions of data text to test whether the different constructions of day care 'fit' the data once the artificial constraints of the coding system were removed.

The findings of the analysis presented in chapters four to seven are, in effect, a presentation of the analysis itself, showing how the different understandings of day care are constructed, or how these meanings are conveyed.

# 3. RESEARCH SETTINGS

This chapter describes the hospice day care units in which the study took place and the reasons for their inclusion in the study. There are five sections. Section 3.1 focuses on the selection criteria used to choose the research settings, and sections 3.2, 3.3, and 3.4 provide a contextual account of the three study sites. The final section provides a brief introduction to the analytic chapters that follow.

The research settings are, in this thesis, called sites A, B and C. The names of the units are not disclosed so as to preserve the anonymity of the participants. It was decided not to use hospice pseudonyms because this involves a moral/political judgement on my part and may unintentionally convey meaning (Parker, 1992). In this respect, referring to each study site as a letter is relatively neutral. It is to be noted, however, that the study sites are similar in that they are all regarded as a 'hospice' rather than a 'palliative care unit'. Two sites have 'hospice' in their official title and although the term is not in the title of the other site, the unit is known and referred to as the 'hospice' for the geographical area. All three units are in the South of England.

## 3.1. SELECTION CRITERIA

Given the length of time considered necessary for the data collection in each site and the lengthy preparatory procedures required to gain access to the day care units for study, it was decided that the study should focus on three day care centres. The day care units selected for study were chosen for three main reasons:

1) Each centre is closely connected to an in-patient unit. As described in chapter one, there are various different types of day care facility and for the purposes of this study it was considered important that all the participating units were of a similar style. The majority of day care centres in Britain are attached to an in-patient unit and for this reason it was considered appropriate for the research to be conducted in this type of facility.

2) The three study sites were also relatively stable, undergoing no changes in organisation, management and/or staffing. Although one unit had been running for only six months, and another had moved to occupy new rooms in the year preceding the study, the patients and staff in all three centres were relatively settled.

3) The final reason for the selection of the study sites lies in their location. All study sites were within an hour's travelling distance. Considering the regularity of the visits required for observation over a period of some months, it was important to limit the amount

of travelling the researcher had to do. It was important for travel time to be kept to a minimum to ensure she could recall and document the events observed in the units.

## 3.2. SITE A

### 3.2.1. The hospice

Site A is a relatively newly established hospice, having opened in 1994. The hospice provides in-patient and day care facilities. Although it liases with Macmillan and home-care nurses, these services are not funded by the unit. The hospice is built on land donated by the owners of the surrounding estate, and is situated in three acres of open countryside. The hospice is a registered charity and is funded mainly through the voluntary sector. Capital and revenue costs are mainly met by donations and fund-raising activities, although the hospice is in receipt of financial assistance from the NHS. The in-patient unit is purpose-built providing 19 beds, although only ten beds were funded at the time of the study. Bedrooms are mainly single, although there are two double rooms to enable partners to stay with patients. All bedrooms have ensuite facilities, television and video. As well as a number of seating areas for in-patients, the hospice provides a multi-denominational chapel, 'jacuzzi' bath facilities, a fund-raising coffee shop and landscaped gardens.

### 3.2.2. The day care unit

Opening six months after the in-patient unit and six months before the study, the day care centre is housed in a purpose-built wing of the hospice building. It is comprised of a sitting/dining room, kitchen, therapy room, toilet facilities and a conservatory. The carpeted sitting room is large and airy with high-backed comfortable chairs arranged round a fireplace. Television, hi-fi/radio and electric organ are provided, set back against the wall, and flower arrangements are distributed throughout the room. The curtains and carpet match the general green décor of the room.

In one corner of the room dining tables and chairs are arranged, and near to these, the patio doors open out into the conservatory, where more comfortable chairs are arranged round a coffee table. Doors open out of the conservatory onto a patio area with garden furniture and flowerbeds. The kitchen is through a doorway by the dining area and is relatively small and white. It is furnished not unlike a 'home' kitchen, with all the usual appliances and utensils.

The toilet area is situated on the entry/exit corridor, behind a wall with pegs where coats are stored. The wall screens the toilets from the main seating area. There are two broad toilet cubicles, each one with hand-rails and wash basin. The therapy room is situated along the corridor, it's door opposite the way out to the hospice reception area. It is a large light room with a central table, a sink and kitchen-style storage cupboards around the walls. Books, puzzles and craft items lie on the shelves. In one corner of the room is a desk, telephone and filing cabinet, and along the wall is a door through to a small treatment room minimally furnished with a couch, chair and hand basin. Jacuzzi bath facilities are along the main corridor leading to the in-patient unit.

### 3.2.3. Days, hours and routine

At the time of study, Site A day care was open two days a week between ten in the morning and four o'clock in the afternoon. Day trips to gardens, fruit farms and staff houses were also held once a month on a third day of the week. Typically, patients were transported to the hospice by volunteer drivers or relatives, and gathered together for a drink in the sitting room and the conservatory. Most of the hospice building was regarded as a no-smoking zone and patients who smoked tended to spend most of their time in the conservatory where smoking was permitted. Patients spent the morning talking amongst themselves and with volunteers whilst the nurses helped individual patients to bath, and carried out clinical procedures such as dressing wounds. Hospice doctors on occasion visited patients. Each morning members of the catering staff circulated the unit taking orders for lunch. Patients were offered an aperitif drink (alcoholic or soft) before lunch at midday. Patients were assisted to their seats at the dining table and their meals were brought round from the main hospice kitchens by volunteers. The nurses took their breaks at this point in the day.

In the afternoon, time was spent watching television, reading, talking, making something, or having reflexology foot massage or beauty treatments. The nurses added to patient notes and carried out general administrative work. At three o'clock everyone gathered in the sitting room for tea and cakes before the transport arrived to take the patients home.

### 3.2.4. Referrals

Patients were referred to day care either by the consultant, hospice physician or clinical psychologist. Home-care nurses, social workers and general practitioners could also initiate referrals, but applications must first have been made to one of the hospice staff above. Referrals were often made to day care from the in-patient unit when the day care leader attended morning team meetings before day care opened for the day.

Of the patients for whom notes could be obtained, most were referred to site A day care for more than one reason. The most common reasons for referral were: recreation, psychological support, carer respite and patient request (see table 1).

Table 1. Reasons for referral

| Reason for referral | number of times cited<br>Site A<br>(n=12) | Site B<br>(n=12) | Site C<br>(n=11) |
|---|---|---|---|
| Patient request | 7 | - | - |
| Recreation | 7 | - | 7 |
| Social support | - | 2 | 4 |
| Psychological support | 7 | 5 | 1 |
| Carer respite | 7 | 6 | 7 |
| Bathing/hygiene | 5 | 1 | - |
| Rehabilitation | 1 | - | 3 |
| Pain control | 1 | - | 1 |
| G.P. suggestion | 1 | - | - |

(Data was collated from patient notes, not all of which were available. More then one reason for referral per patient could be identified.)

Following referral the day care leader visited each patient at home or in the in-patient unit to make an assessment. Some patients (and their carers) made preliminary visits to the unit to see whether they would like to attend fully. Patients were then allocated to a specific day according to patient numbers, and booked in for an eight-week period, extendable according to need. Each patient was re-assessed by the day care leader six to eight weeks later to decide whether day care should continue. If day care was not considered beneficial, the patient was discharged. Day care in site A was open to accept patients with many chronic terminal diseases although, at the time of the study, it was not considered appropriate for patients with HIV/AIDS.

### 3.2.5. Participants

Fourteen patients attended site A day care regularly during the study period. Seven attended on each day the unit was open. The length of time patients had been attending varied from six months (since the unit opened) to two weeks. One patient started day care during the study. There were seven men and seven women, and their ages ranged from 36 to 82 years, giving a mean age of 59 years. All but the youngest patient who had multiple sclerosis had cancer (see table 2).

Table 2. Patient diagnoses

| Diagnosis | number of patients | | |
|---|---|---|---|
| | Site A (n=12) | Site B (n=12) | Site C (n=12) |
| CANCER | | | |
| Prostate | 4 | 4 | - |
| Brain | 2 | 2 | 2 |
| Pancreas | 2 | - | - |
| Breast | 1 | 2 | 2 |
| Oesophagus | 1 | - | - |
| Stomach | - | 1 | - |
| Bladder | 1 | - | - |
| Myeloma | - | 1 | 4 |
| Melanoma | - | 1 | - |
| Bowel | - | - | 1 |
| Leukaemia | - | - | 1 |
| Primary site unknown | - | 1 | - |
| NON-CANCER | | | |
| Multiple sclerosis | 1 | - | - |
| Motor neurone disease | - | - | 1 |
| Heart Failure | - | - | 1 |

(Compiled from patient notes, not all of which were available)

The staff in site A comprised a 'Nurse/therapist', a 'Support Nurse' and a band of volunteers. The Nurse/therapist is a Registered General Nurse of sister grade, who manages the unit and works from nine in the morning to five in the afternoon. The Support Nurse is a care assistant who has no formal nursing qualifications but who is undertaking National Vocation Qualifications in nursing at the time of the study. She is the assistant to the Nurse/therapist and works the hours that day care is open (ten to four o'clock).

There were eight main volunteers working within site A day care. They worked either in the morning or the afternoon for four hours. Two volunteers worked for each period with a change over in the middle of the day. There were also some volunteer drivers who were responsible for transporting patients to and from the unit.

Although the main participants were the attending patients and the nurses and volunteers who were assigned to day care, the unit was visited by many other people during the time of the study. Patients' relatives sometimes joined everyone for afternoon tea, or came for a day to see what was going on. Other people returned to day care to see everyone after their relative, a day care patient, had died. Health professionals also visited. Patients were visited by the hospice physician, reflexologists and on one occasion a home-care nurse. Patients were also seen by physiotherapists and occupational therapists whilst attending day care.

## 3.3. SITE B

### 3.3.1. The hospice

Site B hospice is built on the edge of a hospital overlooking open countryside, villages and downs. It is connected to the adjacent hospital buildings by a linking corridor. As a registered charity, the hospice trust was set up in 1981 and provided funds for a home-care nursing service and raised money to build, equip and run an in-patient 'Macmillan' unit. In 1987 the in-patient unit opened and was independently financed for three years until the local health authority took over the majority of the funding and management.

Initially day care provided a bathing service to discharged in-patients. Patients came into the hospice and waited in the main 'day' room for the nurses working on the in-patient unit to help them have a bath. A nurse was later employed specifically to help these patients. Further monies were then raised to provide an extension of the in-patient unit and a purpose built day care facility. In 1995 the hospice reopened under the current name, and day care came to occupy a specific area separate from the in-patient part of the hospice. The hospice is now a base for a variety of palliative care services including a hospital support nurse and a symptom control clinic, as well as in-patient, home and day care.

The in-patient unit has eight beds open for use and two further beds awaiting funding. The unit has bath, toilet and shower rooms and two sitting rooms for patients. The larger of these two 'day rooms' is also used as a dining room for in-patients and day patients and has a terrace over the hospice wildlife garden looking onto the downs.

### 3.3.2. The day care unit

The day care unit is in a purpose built wing of the hospice on the ground floor beneath the offices of managerial and administrative staff and the home-care nurses on the first floor. It is comprised of a main sitting or 'day' room, kitchen, treatment room, toilet facilities and an office for the day care leader.

The sitting room occupies a corner of the hospice building. Comfy high-backed chairs and coffee tables with flowers are arranged around the walls. The curtains, carpet, chairs and décor of the room are all colour co-ordinated. The room is approximately four metres by eight metres in size with a built in cupboard at one end, a bay window at the other and another window in the long wall. Opposite this window are double doors through to a kitchen area with low sink for disabled access, cupboards, various electrical appliances and a small table.

The name of the day care unit is on a plaque displayed in the corridor just outside the door to the sitting room. The day care leader's office, two large toilet rooms and the treatment room are situated off this corridor. The treatment room is small and overlooks a courtyard garden in the middle of the hospice building. The room is sparsely furnished with a treatment couch, chair, hand basin and storage cabinets. The toilet rooms are relatively spacious each with a lavatory and adjacent hand-rails, wash basin, and a cord pull for the nurse-call system. Opposite the toilets is the day care leader's office with a desk, phone and filing cabinet. Notices, poems and posters line the walls of this small room.

As mentioned above, day care patients have their lunch in the main 'day' room connected to the in-patient unit. This room adjoins the in-patient wing of the hospice to day care. In it, arranged along one wall and around the television at one end, are many comfy chairs. At the other end of the room the dining tables are set out with a chair at each placing. The room also houses sideboards with a radio-hi/fi, books and alcoholic drinks.

### 3.3.3. Days, hours and routine

At the time of the study, site B day care was open five days a week, between half past ten in the morning and three o'clock in the afternoon. Although the nurses were employed to work the hours day care was open, they tended to arrive at least a half an hour early. The patients arrived usually by means of volunteer transport. The patients, and often the drivers, would gather in the day care sitting room with the nurses for a drink. About half an hour later the drivers would leave and the nurses began to prepare baths for patients. Whilst one, or sometimes two, patient were having their baths with the help of the nurses, the other patients remained in the day care room talking with each other or volunteers. Patients who smoked moved between the day care room and the main hospice 'day' room. Smoking was permitted in the main room only. Before lunch, aperitif drinks were offered to the patients. Patients were then escorted through to the main 'day' room adjoining the in-patient unit for their lunch. Meals were served from a large steel lunch trolley wheeled into the hospice from the hospital and placed just outside the 'day' room door. The day care leader served the meals onto plates for in- and day patients at the trolley, and volunteers gave the plates to the patients.

Following their meal, the patients gradually made their way back to the day care room, although some often remained in the day room to watch television or to smoke. Most patients napped in the afternoon, whilst the nurses conducted administrative paper work or helped out on the in-patient unit. Occasionally an aromatherapist came to see patients in the day care room, and outings to pubs and gardens were organised by the day care leader. Drinks were offered later in the afternoon, and everyone gathered together to talk before the volunteer drivers arrived to transport the patients home.

### 3.3.4. Referrals

Patients were referred to site B day care by the hospice consultant or the general practitioner, although other health professionals such as a home-care nurse can make applications. Possible patients were also discussed during the weekly team meeting between staff from all areas of the hospice service. All potential patients were assessed by the hospice consultant before commencement of day care. The reasons patients were referred to day care were difficult to identify because day care had no separate documentation. Notes relating to day care were entered into the home-care nursing files. Despite this, and like those in site A, the reasons patients were referred to day care were varied and often multiple (see table 1, section 3.2.4).

### 3.3.5. Participants

Twelve patients attended site B day care regularly during the period of study. Seven attended on one day, three attended on two days and one patient attended three days a week. This means that the number of patients attending varied from one (on Wednesdays) to five (on Fridays). At the beginning of the study, the patient who had been attending day care the longest had been coming for sixteen months. The patient who attended for the shortest period only attended day care once before she died (and is not included in the figures presented here). Three patients started attending day care during the study period. Seven patients were men, and five were women with ages ranging from 25 to 87 years (mean age

72.4). All patients who attended during the study had cancer, although for one patient the primary site of cancer was unknown (see table 2, section 3.2.5.).

Two nurses worked in site B day care. The day care leader was an enrolled nurse called the "day care nurse", and the care assistant was called a "health care assistant". Both nurses were employed to work the hours of day care, although as previously mentioned, they tended to come in early, and after clearing away at the end of the day tended to finish after the patients had left.

Only three volunteers worked in site B day care. Two helped on Tuesday mornings and one on Thursday afternoons. Day care was also frequented by the volunteer drivers who transported patients to and from the hospice, however these are not considered main day care participants because their duties did not lie in the day centre itself. Day care was visited by many other people. The hospital chaplain and her assistant dropped in at least weekly, and hospice social workers, home-care nurses and doctors also came to see patients whilst they were in day care. The hospice volunteer co-ordinator also called in most days to talk with patients, volunteers and nurses.

## 3.4. SITE C

### 3.4.1. The hospice

The hospice unit of site C is situated within the grounds of a general hospital bordered by tall hedges, car-parking facilities, a wooded area and a road. It comprises of a three-storey house, extensively adapted and extended to provide an in-patient unit and a day care centre. The hospice is also the base for a long established local volunteer organisation specialising in care of the dying. The hospice was built, and is maintained, by donations and support funding from the NHS. The day care service predates the opening of the hospice building. Initially, the volunteer organisation was a registered charity providing a volunteer befriending and support service for dying people in their own homes. The trained volunteers provided by the organisation formed part of the care package alongside home-care (Macmillan) nurses and primary care services. A day centre with a nurse manager was provided by the organisation in a small building within the grounds of the general hospital. The organisation continued to provide day care and respite from that location until 1992, when the hospice building was opened. The hospice now receives half its funding from donations (it is a registered charity) and half from the NHS. The volunteer organisation is now mainly financed through the hospice.

The in-patient unit is located in the extended single-storey portion of the hospice building. At the time of the study there were fifteen beds, however, only ten of these beds were funded. Beds were provided in rooms of varying size: there were three four bedded bay areas and three single rooms. Toilets and bathing facilities were provided separately. There was also a therapy room and a large conservatory at the end of the unit overlooking the garden. The main entrance to the hospice links the inpatient unit to the day centre.

### 3.4.2. The day care unit

The site C day care is located on the ground floor of the original house. The day unit comprises of a sitting room, a dining room, a "quiet" room and two toilets. The day patients also make great use of a therapy room located in the in-patient part of the hospice.

The sitting room is a large room overlooking the hospice garden with a central pond and fountain. The room is approximately six metres by five metres in size and houses about twelve high-backed comfy chairs arranged in a large semicircle. Some of these chairs are located within a large bay window furnished with flowered curtains that match the carpets and general décor of the room. On a white board patients and nursing staff are listed along with an outline of the day's events. This is updated each day. Along one wall is a large glass fronted 'home-style' storage cabinet accommodating books, videotapes and puzzles. On the wall opposite the window is a pin board on which are displayed several drawings and paintings. Along this wall are stored footstools and a number of small tables, one with a telephone.

Through an archway is the dining room, with the tables set up in the shape of a 'T'. In this room, as in the sitting room, a large bay window is sited in the outside wall. Two smaller windows are also located in the adjacent wall. This room is connected to a smaller room through two archways. This anti-room accommodates a bookcase and storage cupboards for the hospice library, day care cutlery and crockery. Through a doorway is the hospice kitchen. It houses stainless steel appliances, work surfaces and a number of large ovens.

The conservatory is located between the windows of the sitting and dining room, and access can be gained through separate doors from both rooms. The conservatory opens out onto a terraced area overlooking the garden.

The toilet facilities are off the corridor leading to the main entrance. These are relatively large rooms each with a lavatory, hand-basin and nurse-call cord hand pull. The corridor leads past the day care sitting room to a staircase allowing access to the offices on the floors above. The corridor also has a cupboard where patients hang their coats, and the door to the small "quiet room". Decorated in green, this room has two windows with co-ordinating curtains, a treatment couch and several comfy high-backed chairs.

The therapy room, located by the in-patient unit, is approximately four by five metres in size. A number of smaller tables are arranged in the centre of the room to make one large central surface. On corner of the room is devoted to physiotherapy with a treatment couch and equipment sectioned off with a curtain and rail to afford some privacy from the rest of the room. All around the walls of the rest of the room are storage cabinets for, and piles of, art and craft materials. In another corner of the room by the sink is the occupational therapist's desk and phone, covered with paper and other materials.

### 3.4.3. Days, hours and routine

At the time of the study, site C day care was open between ten in the morning and three o'clock in the afternoon on two days of the week. Apart from day outings approximately once a month, this day care unit ran an ordered programme of activities for each day. At half past nine, before the patients arrived, the nurses and volunteers gathered together for a "briefing" to talk about the patients and prepare for the day. At ten o'clock the patients, having been transported by volunteer drivers, gathered together in the sitting room for drinks and biscuits. Around twenty minutes later group physiotherapy commenced. The patients remained in their chairs and did gentle exercises under the direction of a physiotherapist.

At half past ten, the patients moved into the therapy room for art and craft activities. During this period, individual patients also had physiotherapy, aromatherapy and/or hair dressing. Aperitif drinks were served before lunch at quarter past twelve, after which patients were escorted to the dining room to take their places at the large table. The chef served the meals, prepared in the hospice kitchen, from a 'hot-plate' trolley pushed into the anti-room adjoining the kitchen and the dining room. The volunteers waited on the patients and then some joined the patients and nurses for their meal.

The morning and afternoon volunteers changed over during the lunch time period. After lunch some patients were escorted to the quiet room. On one day a relaxation session was held, and on the other day, patients were able to have an afternoon nap. After the relaxation session, there was a chapel service specifically for day care patients conducted by one of the chaplains. If not attending the relaxation session, the chapel service, or having a sleep, patients gathered in the sitting room to talk, read or do puzzles. At this time the day care leader wrote notes, either in her office on the second floor or in the sitting room with the patients. At two o'clock everyone gathered together for tea and cakes baked by the volunteers, before the volunteer drivers returned to take the patients back to their homes.

Site C day care also held a monthly carers support group, on a morning when day care was not open to patients. Patient's relatives were able to talk to other carers, to the day care leader, a trained volunteer, a home-care nurse and/or the volunteer co-ordinator. As well as tea, coffee and biscuits, carers were offered aromatherapy.

### 3.4.4. Referrals

Referrals were formally made to site C day care by either the hospice consultant or the patients' general practitioner, although applications were often by primary health care professionals, other hospice staff, carers, and patients themselves. One patient found out about the day care from his local library and then made enquires at the hospice himself. Another patient found out about day care from her local motor neurone disease support group. Having received a referral, the day care leader then assessed the patient, and potential patients were invited to spend a preliminary day in the day unit to sample the activities. Like the patients in sites A and B, most patients attending this day care were referred for more than one reason, however most patients were referred for carer respite, recreation and diversional activities and for social support (see table 1, section 3.2.4.).

### 3.4.5. Participants

Fifteen patients attended this day care regularly during the period of study. Ten patients only attended on one day, and five patients attended on both days the unit was open. This means that overall, there were nine patients on one day and ten on the other. The longest attending patient had been coming to day care for over four years. Four patients started attending day care during the period of study. There were six men, and nine women and their ages ranged from 32 to 86 years (mean age 63.4). Most of the patients had cancer, although one patient had motor neurone disease and another end-stage heart failure (see table 2, section 3.2.5).

As with sites A and B, there were two employed members of staff working in day care, both of them nurses. The day care leader was called the "day care sister" and was a Registered General Nurse of sister grade. The other day care nurse was formally a "nursing auxiliary" although participants never referred to him as such, preferring to call him by his first name. He had no formal nursing qualifications but had some nursing experience and worked in the in-patient unit on the other days of the week.

There were twenty-five volunteers who regularly helped in site C day care. They worked for either morning or afternoon periods, although some occasionally worked for entire days. Morning volunteers came in for team briefing at half past nine and left at around one o'clock. Afternoon volunteers arrived at around half past twelve for a briefing before they took over. These volunteers left day care shortly after the patients were taken by the volunteer drivers at three o'clock.

Other people who visited day care in site C include Red Cross 'hand ladies' who gave hand massages and beauty treatments, voluntary reflexologists and aromatherapists. Day care was routinely visited by a physiotherapist (as described above) and often by the occupational therapist, and the volunteer co-ordinator dropped in frequently. Two hospice chaplains visited the patients weekly, and health specialists to whom the day care leader had referred patients came in on occasion. Some in-patients also attended day care during a stay.

## 3.5. PREFACE TO THE ANALYTIC CHAPTERS

The term 'discursive environment' has been developed to encompass all the components of a setting which have a role in the construction of meaning. This term is considered appropriate because it represents the inclusion of *material* as well as *discursive* elements in the analysis. Whilst the word 'discursive' is pertinent because much of the analysis focuses on language use, the term 'environment' is considered relevant because it is often equated with material existence, physicality or what is 'out there'. As described in section 2.1, meaning is conveyed by the aspects of the physical environment and what people do, as well as how they talk. Although the understandings that are explicated in chapters four to seven could be described as 'ethnographic descriptions' or 'social constructions', within this thesis the term 'discursive environment' is considered more appropriate.

'Discursive environment' is an inclusive term referring to both the material and discursive elements of a setting. A discursive environment is not 'real' in a material sense. Rather, it is a construction, a web of understanding imbuing a particular physical setting with meaning. Although emphasis is placed upon the role of language in the construction of a discursive environment, non-verbal behaviours, aspects of the physical context and the general organisation of time, space, and people, are also considered significant. Variability in these components means that one setting or context can be construed in many different ways. To prevent reification, each discursive environment detailed is enclosed within quotation marks (' ').

For the purpose of writing a thesis progressing in a sequential format, the findings of the analysis are presented as four separate chapters. This implies that the four understandings of day care expounded therein are clearly and easily segregated. However, in practice the different meanings overlap and merge and are constantly being modified, and so division of the constructions could be said to be somewhat artificial. Similarly, the categorisation of components of the day care setting serving to construct each discursive environment can be considered somewhat artificial. Each chapter, revealing the construction of a discursive environment, is divided into three main sections. These sections detail: 1) 'structural features' of the discursive environment (the organisation of time space and people); 2) the 'work' of the discursive environment (what is done: the actions of the participants); and 3) the 'social relations' of the discursive environment (the distribution of power amongst the participants). Apportioning a particular component to one or other section of the chapter implies that the classifications are mutually exclusive. This is not the case. The boundary between what can be considered a 'structural' feature, or an aspect of 'work', or part of the 'social relations' of a discursive environment, is not distinct. A more appropriate format for presentation, although not possible here, may be a form of 'hypertext'.

A final point to be made with reference to the analytic chapters refers to the labelling of participants as either 'patients', 'nurses' or 'volunteers'. This categorisation is used to reflect the division of day care participants according to the reason they are in attendance and the roles assigned by the hospice itself. The term 'staff' is used to refer to both the paid and unpaid workers (primarily nurses and volunteers). Although the nurse who manages day care and the nurse who assists her are given different titles in the three sites, in this thesis they will be referred to as the 'day care leader' and the 'care assistant' respectively.

## 4. THE 'OUT PATIENT CLINIC'

The discursive environment of the 'outpatient clinic' draws upon medical discourses, constructing day care as a specialised clinic for monitoring the symptoms and treatments of patients' illnesses. Material, as well as discursive, features of the day care setting contribute towards the construction of the 'clinic'. The social relations accompanying this discursive environment reflect the unequal distribution of power. Nurses are construed as 'medical experts', active doing the work of the 'clinic'. Patients however, are constructed as 'passive recipients', or objects of care. As such, patients take on subordinate positionings within the environment. This 'authoritarian' distribution of power is inherent within the material and discursive context of day care as a 'clinic'.

### 4.1. THE 'SPECIALISM' OF HOSPICE DAY CARE

Medical discourses are used to raise the profile and legitimise hospice day care. Terminology associated with medicine is used to construct hospice day care as a 'specialised' form of day care that is distinct from other day care services.

> Extract 1: Field notes STH1-2 lines101-113
>
> [ ] L [DCL] went on to say that she didn't know whether the hospice day care is appropriate for Jm [PT] any more, and that a "normal" day care may well be more appropriate. I asked her what a "normal" day care was like. She said that it isn't like this "specialist" day care which provides baths and dressings. She had run one in her village. It's "more social" with more people where they play games.[ ]

In this example, the day care leader refers to the medical and nursing 'specialism' of hospice day care, pointing to the type of services that are provided. Use of the term 'specialist' refers to the specialism of Palliative Medicine, and implies hospice day care is superior to other "normal" day centres. This raises the profile of hospice day care and gives prestige, and as such legitimizes it's existence. The use of the term 'specialised' also implies that the providers of the service, are 'specialists' or experts in the field of palliative care. The use of medical discourse in this situation, therefore, not only alludes to the superiority of hospice day care, but also elevates the status of the nursing staff.

The notion that "normal" day care is "more social" than hospice day care, is a view voiced elsewhere. In the following interview extract a care assistant talks about what goes on in "ordinary" day centres:

Extract 2: Care assistant interview E-10-4 lines 511-534

E: [ ] Well from what I've heard of them I think they sort of tend to sit and chat, and have endless cups of tea, probably play cards, or do bingo or something, you know.

AL: Yeah, yeah.

E: But, I mean, I don't think they, I don't think they sort of do the outings and that that we try and do here for patients. But obviously an ordinary day centre, I mean, obviously the people that go there are not going to be as poorly as our patients are they? [ ]

The care assistant's understanding is that other day centres are for socialising: chatting, playing games and drinking tea. The care assistant also implies by her use of the term "ordinary", and the reference to "*endless* cups of tea", that other day centres are everyday and mundane. On it's own, this further implies that hospice day care is different: offers something over and above 'ordinary' day care. The nurse goes on to substantiate this claim by saying that ordinary day centres do not "do the outings" provided with hospice day care. The care assistant finally draws upon a powerful medical discourse, to further draw a distinction between hospice day care and other "more social" day centres: "ordinary" day care is for "people", whereas hospice day care is for "patients", who are "poorly". The repeated use of "obvious" signifies that this 'medical' distinction is beyond doubt and incontrovertible.

From these examples it can be seen that hospice staff call upon medical discourses pertaining to the 'specialism' of hospice day care for 'patients', when comparing the service with other day centres. Aspects of the day care environment also reflect the use of medical discourses in the construction of the clinic. The material features of the building and the participants as well as aspects of organisation contribute towards the structure of the clinic.

## 4.2. THE STRUCTURE OF THE 'OUT PATIENT CLINIC'

Material features also contribute to the construction of day care as a clinic. Day care exhibits some structural characteristics of clinic settings pertaining to traditional medical settings, where the medical surveillance and treatment of patients is paramount. The allocation of time, space, staff and equipment to such medical matters in hospice day care serve to construct a clinical environment. Uniforms, appointment systems, waiting rooms, shifts, breaks, briefings and handovers, all constitute the material surroundings of a clinic.

### 4.2.1. Uniforms

Traditional nursing uniforms are commonly associated with those who work in medical settings. In two out of the three sites, all nursing staff wore uniforms. In site A the nurses wore dresses in line with traditional nursing uniform, and in site B the nurses wore nursing tunics and trousers. In both cases, the grade of the nurse was signified by the colour of the uniform, and was written on name badges worn on the chest. The site A day care leader also wore a fob watch. In site C, the day care nurses wore everyday clothes, indistinct from those worn by the patients. The wearing of a uniform implies that medical or nursing tasks are to be carried out. By wearing everyday clothes, the nurses in site C avoided this set of expectations and therefore appear less 'medical'.

Volunteers in all three study sites also had a uniform which consisted of a tabard worn over everyday clothes. Again in all three sites, volunteers wore name badges. In sites A and B name badges were worn by nurses and volunteers. In site C, fun badges fashioned by one of the volunteers, were worn by the nurses, volunteers and patients. In contrast to the formal identity badges worn elsewhere, these 'home-made' badges lessened the distinction between 'patients', 'nurses' and 'volunteers' and as such, countered the perception of day care as a medical setting.

In all three sites, no uniforms were worn during trips out. On these days, no clinical procedures were carried out; emphasis was on having fun rather than treatment. Volunteers also took off their tabards when accompanying patients outside the hospice grounds. If accompanying a patient for an outpatient appointment, however, volunteers remained in their tabards. Here, as with the nursing uniform, the volunteer uniform is an accompaniment to the medical function of day care.

### 4.2.2. Appointments

On many occasions, patients attend hospital outpatient appointments during day care hours. Patients have appointments for audiology, x-ray and dentistry, as well as consultations with doctors. Nurses are responsible for making referrals and arranging appointments, and volunteers are often sent to accompany patients.

In addition to attending day care for 'formal' appointments elsewhere, some patients attend specifically for 'informal appointments' in day care itself, for example:

> Extract 3: Field notes STH21-3 lines 81-95
>
> [ ] At 10.20 a white uniformed woman came in greeting Jm (PT) and E (CA), and saying a general hello to Dn (PT) and me. She carried a little green bag. She came over to me and introduced herself, 'Sl'. I said a little about my work and she then turned to Dn and introduced herself and he said that he had come into day care for aromatherapy. She then arranged to give Jm some aromatherapy, putting his feet up on a stool covered with a towel and pulling out various jars and smelling them [ ]

On this and other occasions, the patient (Dn) mentioned coming in to day care solely for an aromatherapy session. In the following field note extract, it is a relative who construes day care as a place in which procedures are carried out and that patients only attend for specific appointments.

> Extract 4: Field notes BF27-9 lines 83 -94
>
> [ ] Dy [volunteer co-ordinator] then stepped in saying that Ky's [PT] husband is very angry. [ ] KC [SN] said that she had spoken to him during the week when there was a problem and had dealt with it and Dy said that as far as he's concerned the only reason Ky is coming to day care is for a haircut and he was very angry last week that she didn't have one when she came in [ ]

It can be seen that, in this day care the relative's reported view that his wife attends day care "only" for a haircut is 'problematic' for the staff. The volunteer co-ordinator, by saying in her description of the relative's view of day care that having a haircut is the "*only* reason" for attendance, implies that there are many other reasons why patients may come to hospice day care. The relative is said to construe day care merely as a holding point for patients awaiting appointments, whereas the staff understand day care to be something more. This demonstrates the different ways in which day care can be construed, which can set up tensions between the various participants. In this example, the relatives reported view of day care is consistent with the notion of a clinic: a place to go for appointments.

At busy times in day care, 'informal' appointment systems are in operation for the activities such as physiotherapy, aromatherapy and bathing. There were frequent references to the "queue" of patients wanting a bath, and in some instances, patients had to wait until their next visit, some days later. For example:

> Extract 5: Field notes 3-8 lines 95-101
>
> [ ] Ls [PT] asked An [VOL] if he could have a bath this afternoon. An called to T [DCL]. T explained that she is only able to do two in one day so that she couldn't today but that next week they could do it. [ ]

### 4.2.3. Waiting rooms

Common within other medical environments, the main day care room in site B is at times construed as a 'waiting room'. This was evident on a number of occasions when the researcher asked patients about what happens in day care.

> Extract 6: Field notes SF19-1 lines 221-225
>
> [ ] I asked him [PT] what happened in the afternoon. "We go back in there, the 'waiting room' and do the same as in the morning", he said.[ ]

Asking a different patient what went on in the morning received a response implying that nothing very much had happened.

> Extract 7: Field notes SF8-3 lines 51-58
>
> [ ] I went into the sitting room and asked Bi [PT] if he minded me sitting next to him, and sat down. I asked what had happened this morning and he raised his eyebrows and shook his head with an expression of "don't know" as if I'd asked a trick question! [ ]

The facial expression of the patient signified that he had spent some time in day care waiting. As well as waiting for 'formal' and 'informal' appointments, patients wait for the nurses to return:

> Extract 8: Field notes SF19-1 lines 343-345
>
> [ ] I asked Br [PT] what happens in the afternoon: "wait for them to come and talk to us" [ ]

The 'waiting room' mentioned in extract six refers to the main day care sitting room in site

B. In each site, the main sitting room is an area patients can occupy comfortably. Other areas of the sites, however, were informally designated as staff only areas. Two sites had integral kitchen areas which were largely used by the nurses and volunteers. Only on rare occasions did patients enter the kitchens. The following extract describes an incident when a patient joined nurses and volunteers in the day care kitchen.

> Extract 9: Field notes ST26-3 lines 146-160
>
> [ ] Jo [PT] returned. She was angry. She described how she had been in the kitchen with Li [VOL] saying hello to H [VOL]. Sn [volunteer co-ordinator] was in there too. H had just given Jo a square of toast and Cln [SN] had walked in and "glared" at Li and herself. Cln then mumbled to Sn taking her out of the kitchen into the sitting room and talked "about us" (Li and Jo). Sn came back in and asked Jo if she would go back to day care and she and Li left saying to H that they wouldn't stay where they weren't wanted [ ]

In this extract, the patient describes how she was made to feel she was somewhere she was not wanted; that she had entered a 'staff only' zone. The event is all the more interesting because the kitchen is described in the hospice leaflets as an "activity kitchen", which implies it's use by patients.

The day care rooms represented different territories for nurses, volunteers and patients. The patients' area was the sitting, or "waiting" room, and the kitchen was construed as a staff area. This is comparable to medical settings, like clinics and wards where there are marked nurse and patient territories.

### 4.2.4. Shifts

The nursing staff and volunteers all worked in day care according to specific 'shift' patterns. The nursing 'shifts' were unlike the traditional 'early', 'late' and 'night' shifts of many clinical ward settings, but were more consistent with the '9 to 5' shift patterns of nurses working in outpatient departments. Like outpatient nurses, the day care nurses' shifts corresponded to the hours that the doors were open to patients. Consequently the nursing 'shifts' were not immediately apparent to participating patients, as they were rarely present at times when nurses came on or off duty. Nurses were also flexible in the times they started and ended their shifts, allowing for patients who were early/late to arrive/depart. As a result, nursing shifts were generally seen to be unbounded in that the nurses were always on duty when patients were in day care: if day care was running then the nurses were on duty. This is perhaps unlike clinical ward settings in which nursing shifts are clearly bounded, their start and finish easily witnessed by patients.

Nursing shifts in day care rarely became transparent to patients, and where they did, tensions were created. The following field note extract describes an interchange between a care assistant and a patient:

> Extract 10: Field notes STH21-3 lines 96-105
>
> [ ] ]m [PT] asked where L [DCL] was joking that she was late and E [CA]came out of the kitchen saying that "actually" L was not late, that "officially, we don't start until 10.30, so you shouldn't be here yet. You're here early.". Sl [VOL] agreed repeating what E said and laughed. Dg [PT] said "Oh dear, we shouldn't be here.[ ]

The nurses' shift and day care, were not due to start until 10.30. The care assistant made plain that day care was restricted to the times of the nursing shift. The care assistant's use of the word "officially", alludes to the formality and rigidity of the nursing shift, adding greater force to her statement.

The shift pattern of the day care volunteers was more overt than that of the nurses. Sites A and C had formally organised rotas drawn up weeks in advance, and the volunteers in site B attended on a set day and time each week. In sites A and C there were morning or afternoon shifts, with a change over of volunteers around lunchtime. At the beginning of each shift, volunteers were involved in either planned briefings or informal handovers.

### 4.2.5. Breaks

Although the nursing shifts were usually 'hidden' from patients, in sites A and B, the breaks allocated within the shifts were overt. There was often overt negotiation between the day care leader and the care assistant about the timing of their breaks, and they went to another area of the hospice, most often a "staff room". At lunch time, segregation was the norm in two day care sites. In site A the volunteers served the lunches to patients while the nurses took their break, and in site B, the nurses and volunteers served lunches to the patients and then the nurses went away for their break. In site A, the researcher's tendency to eat with the patients concerned the staff. The following extracts describe one such lunch time event and the researcher's reflection upon it:

Extract 11: Field notes 5-7 lines 362-380

[ ] At about 12.30 I helped P [PT] to her seat at the table, and sat opposite J [PT] who joined us at the table a little later. D [PT] remained inside lying on the sofa. M [CA] came out and asked if I was "comfortable" and said that I could eat in the staff room if I liked. I didn't have to eat "out here with the patients" on the patio. I said I was happy to eat here. She said that I could eat in the staff room if I wanted to, and that it could provide " a bit of a break". She looked quite earnest, her expression was one of concern. She said that Fridays are "family days" when everyone eats together. I said I was okay to sit outside. M went inside [ ]

Extract 12: Field notes 5-7 lines 426-436

[ ] I feel that I am considered by the staff as a member of staff. E.g. V [temporary DCL] assigning me to the "STAFF" category on the day outing list. I must be careful, without being rude, to be impartial and concentrate on the patients. I had the feeling I was committing a grave sin by having lunch with the patients. M seemed most insistent.[ ]

In extract 11, the care assistant asked after the researcher's "comfort" in lunching with the patients. This may reflect the nurse's *dis*comfort with the situation, as does the repeated statement (perhaps a request) that the researcher could eat in the staff room; the word, "could", may be better read as "should". The nurses here identified the researcher as a member of staff and as such expected her to behave according to the convention that lunch is consumed away from the patients in the staff room.

Although in two sites the nurses did not eat lunch with the patients, in all three sites the nurses, volunteers and patients took morning coffee/tea together. However, in site B nurses and patients used different crockery; the nurses used mugs and the patients were given cups and saucers.

## 4.2.6. Briefings and handovers

In site A there were no formally arranged briefing sessions. Despite this, informal reporting occurred between the nurses and volunteers. Concerning major changes in patients' conditions and circumstances, volunteers reported to the day care leader and the day care leader reported to the volunteers as can be seen in the following two extracts:

Extract 13: Field notes 5-7 lines78-92

[ ] I went back into the therapy room. V [temporary DCL] was in there talking to the woman volunteer who had brought in D [PT]. I didn't enter and waited outside reading notices until they had finished (they were sitting at the desk talking closely) [later] V told me that the volunteer driver who brought in D was concerned about him, he's not very well. She is now trying to arrange for him to be admitted to the in-patient unit..[ ]

Extract 14: Field notes13-7 lines 21-26

[ ] I went into the kitchen behind An [VOL] to get a drink of water. T [DCL] came in and said to An that E [PT] would be coming in today and his wife died on Friday so he would be "fragile" [ ]

The volunteers in site A had their own informal handover of information, usually in the kitchen. They congregated at the shift changeover and talked in lowered tones.

Extract 15: Field notes 5-7 lines 405-409

[ ] At 13.00 I sat in the day area writing a few notes. B and Mo were in the kitchen with two other volunteers, chatting quietly. At 13.10 they came out [ ]

Talk was often about the patients, and major events such as deaths:

Extract 16: Field notes 6-7 lines 384-389

[ ] At 13.00 Joi, an afternoon volunteer, arrived. She went into the kitchen with An where they had a hushed conversation, passing on information about who had died [ ]

These informal handovers were mainly covert, carried out either beyond the earshot of the patients, or in whispers with hands over mouth, and backs turned to the patients, as is illustrated in the following extract which describes two volunteers talking.

Extract 17: Field notes13-7 lines 436

[ ] Joi arrived. An patted the sofa next to her and asked Joi to "come and sit here".

She sat on the sofa. An turned her back on B and Iv [PTS] and the dining area behind us and spoke very quietly to Joi about the death of E's wife. [ ]

Like site A, Site B had no formally organised briefing or handover, however volunteer drivers often went into the day care office to discuss the patient he/she had transported to the hospice. The following extract describes a handover of information about the patient's condition.

Extract 18: Field notes SW20-3 lines 39-45

[ ] At 10.20 A [PT] and S [VOL] arrived. S asked who was going to make drinks looking at me so I took orders and made drinks. While A stood in the doorway S 'reported' to E [CA] that A's leg is painful. E and S went away into the office. [ ]

In the following extract it can be seen that volunteers may 'report' to a nurse, even when it is not what the patient wants:

Extract 19: Field notes ST13-2 lines 83-87

[ ] He [VOL] said to E [CA] that Jo [PT] had said that she had a sore arm and leg and that he was telling E this because he knew that she wouldn't tell them. Jo told S he was a sneak. [ ]

Site C had formal briefing sessions each morning before the arrival of patients. These sessions mainly involved the nurses and morning volunteers. The volunteer co-ordinator/ Community Liaison and the occupational therapist also attended frequently. These sessions were formal in the sense that they were a pre-arranged part of the everyday routine of day care, and took place with participants seated around a table. At the volunteer changeover, the day care leader held a shortened briefing session in the quiet room while the patients had lunch. These sessions allowed the nurses to inform and instruct volunteers about the condition and treatment of the patients, and enabled everyone to exchange observations and ideas. The morning briefing was directed by the day care leader and was loosely structured. Following an exchange of greetings, participants briefly considered matters to do with day care planning and organisation, then got on with "the business": talk about patients, and finally, tasks were allocated to the volunteers. The following extract details the main "business" element of a morning briefing. A is the day care leader, R is the care assistant and MH and Wd are both volunteers.

Extract 20: Conversation transcript BC20-9 lines 1-226

A: Just have a quick gallop through. My: no change. Ny: well I've just talked with [husband] she's really not very well at all. She's in bed. She's vomiting, her pain's not under control, she's constipated. You name it she has it.

[talk about possible admission to in-patient unit and lack of control of patient's symptoms]

A: H: again, just, just a frail old man really I mean, continuing to thoroughly enjoy himself in day care, and he chuckles and laughs away. Joins in, lots of banter

MH: Mmm, yeah.

A: D: well she's going on holiday tomorrow, down to [place name]. M?

R: I spoke to M this morning [she's an in-patient at the moment] I said 'we'll give your love M', she's not very well, she's vomiting and she's tired and er, just not very well at all.

[talk about M coming round to day care]

A: Pl: er, again not very much change in Pl. Pe: status quo with him, no change. Watch his diet, remember that he's an insulin controlled diabetic. Ek: she had a real slap in the face - was it last Friday? It was wasn't it?

R: That's right, yeah.

A: that dial-a-ride won't take her about any more. I'm not tying to blame them.

Wd: Why on earth not?

A: She's got a modified wheelchair, they can't harness it in.

[talk about modifying wheelchair]

A: W: again few problems with W. Morning P [greets unit manager who walks past]. He [patient] has got a sore on his bottom which bothers him. But I found him brighter last Friday when he'd been for a little while. K: a new patient. She's in her seventies, and she's got breast cancer, fungating breast cancer. The more, the major problem with her is really social: she and her husband fight like a cat and dog.

[talk about relationship and meaning of 'fungating'.]

A: She also suffers from depression, and she's also got borderline Alzheimer.

Wd: Good grief!

A: No, she's a very withdrawn person, very very withdrawn.

[talk about relationship]

A: Somewhere this morning I'm gonna have to find time to dress this breast as well, 'cos it needs daily dressings. [ ]

The format of "the business" section of the briefing session was conducted from a list of patients in the diary lying open on the table. The participants talked about each patient in turn, the day care leader calling out the names and providing a summarising statement of each patient's general health status. If volunteers were unfamiliar with a particular patient, or a patient's condition had changed, the day care leader talked about his/her diagnosis and/or the specific requirements relating to the patient's condition. Once the leader had spoken, the care assistant and volunteers added their observations, commented on ideas and asked questions concerning the patient.

Both the format and content of the briefing sessions contribute towards the construction of day care as a clinic. Although not all formally planned events, the briefings have parallels with the traditional nursing handover, where priority is given to the discussion of the patients' condition ("the business"). Briefings are important in enabling both nurses and volunteers to carry out medical surveillance: clinical procedures such as dressing changes and catheter care are planned, diagnoses, symptoms and treatments are discussed, and dietary monitoring is encouraged. Like traditional nursing handover, day care briefing is, in essence, conducted behind closed doors away from patients; the nurses and volunteers talk quietly and/or in another room. This occurs even when the patient is aware he/she is being discussed as in extract 19.

Having outlined the structural features of the 'out patient clinic', attention now centres on what goes on in the three sites; how the verbal and non-verbal actions of participants contribute towards the construction of the clinical environment of day care.

## 4.3. THE WORK OF THE 'OUT PATIENT CLINIC'

The actions of the nurses, patients and volunteers pertaining to day care as a clinic relate to the medical surveillance and treatment of the patients. Although volunteers are involved in the observation of patients, and as such have a role in the medical surveillance of the patients, the nurses do the majority of the medical 'work'. Medical work refers to the performance of clinical procedures, and talk about issues concerning the body, health and illness.

### 4.3.1. Clinical procedures

Clinical procedures commonly carried out in day care include dressings, catheter care, blood taking and testing, and drug administration. Most of these procedures require the nurse or other health professional to 'do' to the patient. As such, the patient is 'done to'. This approach was evident whenever wound dressings were to be changed.

Extract 21: Field notes BF27-9 lines 77-81

[ ] KC [SN] said that A [DCL] had spoken on the phone to her about Ky [PT] saying that she needed a dressing done and that she'd do it this morning sometime.[ ]

Many of the clinical procedures conducted are carried out at the nurse's, rather than the patient's, convenience. In the following extract, the day care leader decides when to assess the patient's new wound:

Extract 22: Fieldnotes13-7 lines 177-185

[ ] T [DCL] asked E [PT] about a wound on his right hand covered by steristrips and tegaderm [dressings]. He said that a man had shaken his hand and it had torn his skin. T had a closer look and said she'd have a look at it later, and cut off the ragged bits of the dressing but saying it was probably best left intact.[ ]

In the following example the patient was asked if the nurse could look at his catheter bag, and he was taken to a less public place for this to be done.

Extract 23: Field notes 6-7 lines 365-368

[ ] T [DCL] came in and asked Bi [PT] if she could have a look at his catheter now. She helped him out of the room. [ ]

Although the patient was asked, he was not in a position to be able to refuse the nurse's request. This again illustrates how nurses do procedures to patients, when it is convenient to the nurse not the patient.

Another clinical procedure commonly carried out in day care is the testing of blood sugar level of patients with diabetes. As with other procedures, staff 'do' to patients.

Extract 24: Field notes SF2-2 lines 50-64

[ ] Et [PT] said she didn't know whether she was allowed some [cake] because she's diabetic and that I had better ask L [DCL]. I did so and she came back and took a blood sugar level measurement from Et. L asked out loud to everyone in the room if they minded her pricking Et in the room. I sat between Et and B [PT] in the window. L said that Et's blood sugar level was 9 mmols so she was okay to eat some cake but added "Don't you have anything else to eat". Et looked at me with raised eyebrows and ate her cake. [ ]

In this instance, some degree of choice was offered to the patients regarding the day care leader conducting the procedure in the 'public' space of the lounge. Once the blood test was complete, the nurse then went on to give the patient prescriptive dietary advice, a major component of medical talk.

### 4.3.2. Medical talk

Talk between patients and nurses associated with day care as a 'clinic' concerns issues to do with the body, health and illness. Patients describe their illness, symptoms and treatments, as well as talking more generally about medical or bodily issues not directly related to their diagnosis. The medical talk of the nurses with patients mainly involves advice giving, and is oriented towards activity or problem solving. This is demonstrated in the following extract.

Extract 25: Field notes SM4-3 lines 22-50

L [DCL] came in and crouched in front of Br [PT] asking how she was. She said that she had had a bad weekend because her mouth was sore. She had a headache too. She also has a "bad stomach". She hadn't wanted to get up this morning. L asked her if she was or had been constipated. Br went to get up saying that her trousers weren't yet up properly because they'd been in a rush this morning. L helped her to stand and tucked in her clothes and pulled her trousers to her waist. L asked her if she had had any painkillers at home. Br said she had had some last night but that they had run out. They were going to get some more today. L looked at me during this interchange. She asked again if Br had had any painkillers this morning and when Br said no, she asked Br if she would like some: yes. L asked again about the "diarrhoea" and commented that just fluids would be best today. Asked if any pain:

> yes in her back, L said that was her "normal" pain. L then went away to get Br some painkillers. [ ]

In this instance, the 'medical talk' was initiated by the patient who responded to the nurse's question, "how are you?", by mentioning aspects of her physical condition (sore mouth, headache and "bad stomach"). The question "how are you?" is commonly used as a form of general enquiry on greeting an acquaintance. The patient could have responded in a more general manner, without reference to anything medical. The sore mouth and headache were common problems for this patient and the nurse chose to ignore these seeking only to find a cause for the 'new' problem of a "bad stomach". The nurse then seeks to resolve the pains by asking if the patient has had any painkillers. Despite being given an answer, the nurse repeated the question while looking at the researcher. Prior to the patient's arrival, the nurse had talked to the researcher about her suspicion that the patient was receiving painkilling drugs at home before coming to day care. This gives some meaning and significance to the nurse's repeat questioning and her look at the researcher: the nurse doubts whether the patient has given her the 'correct' information. It is interesting that the nurse goes on to enquire more explicitly about the patient's pain, despite the patient's previous complaints, and her repeated acceptance of the offered painkillers. The patient admits to having back pain, or as the nurse puts it, her "normal" pain. A further point to note is that the "bad stomach" mentioned by the patient, is substituted by the nurse to the term "diarrhoea", a medical expression. The nurse then gives dietary advice of fluids only, before going to get some painkillers. In this example, both patient and nurse engage in 'medical talk': the patient talks about her symptoms and the nurse attempts to find causes and a solution to these, giving advice and providing drugs.

Medical talk is not necessarily associated with the patients cancer (or other) diagnosis. In the following extract talk concerning the patients illness and treatments leads on to talk about a health issue not within the medical specialism of palliative care.

> Extract 26: Field notes SW24-1 lines 208-259
>
> [ ] L [DCL] walked in to say good bye to A [PT] because she was going early, and they got talking. [ ] They talked about her steroids, how she had reduced them but hadn't been able to wake up yesterday, so they have been increased again. She said she wanted to stop taking steroids. They talked about her weight (she's got a rounded abdomen and a moon face, classic of steroid treatment.) L said that she had lost weight from her feet and legs and patted her tummy saying something like, "I

> don't know about that". A said that she now has arranged to see her doctor once a week. L agreed this was a good idea to keep a check on her. A commented that as L knows, she doesn't like doctors. She said that [General Practitioner] had diagnosed her with Bell's palsy and not "the brain" and so now she doesn't trust her. L said that it was an easy mistake given her symptoms. A said that she's got to go in to have her coil out. She promised to get it done by Easter. E [CA] came in and sat in the chair by the kitchen. L said that if she needs to have it taken out it should come out and asked when it was due out: September. L gasped and said that she doesn't know any "gynea" but that it sounds like it must have to come out, what with the possibility of infection. A said no. E said some things, calling A a "silly girl". L then tried to think out loud how A could have her coil removed with the only woman in the GP practice being A's doctor. She mentioned the health clinic. A eventually said that she should make the effort to go back to the doctor because it was an "honest mistake" (referring to the misdiagnosis), and said that she wished she hadn't said anything now. L and E said that they would keep on at her now until it's done.[ ]

In talking about the side effects of her steroid treatment and the need for the doctors to keep a check on her, the patient mentions her reluctance to see her General Practitioner because of the misdiagnosis of her brain tumour ("the brain"). She goes on to talk about the need to have her contraceptive coil removed but has not seen her GP about it even though the device was due for removal four months earlier. Here the patient's focus is on her reluctance to see her GP and the reason for this. The nurses concentrate, however, on the patient's need to have the coil removed. Although the nurses could be said to be "blocking" the patient's discussion of an issue which distresses her (the misdiagnosis of her condition), the nurses are fulfilling what is expected of them in a medical talk situation. The nurses attempt to give advise on an issue that they admit is not within their expertise, but because it is to do with something 'medical', it is considered a legitimate thing to do. They seek to find a solution to the problem. The problem they seize upon is medical, or to do with the body (the contraceptive coil), rather than the issue of misdiagnosis and the psychological consequences for the patient.

Medical talk here concerns aspects of 'the body' rather than 'the mind'. Moreover, within medical talk, staff are recognised first and foremost as nurses. Consequently, talk about *any* medical or bodily matter is considered appropriate, even though it may be outside the 'expertise' of the nurse, and may concern issues intimate and personal to the patient. In the extract above the nurses pursue problem solving and advice giving activities. However, patients talk about their problems in order for the nurse to provide a solution and give advice. In the following extract a patient tells the researcher about her condition.

> Extract 27: Field notes BF30-8 lines 189-208
>
> [ ] Ny [PT] told me that she wasn't feeling too well. She had an "upset stomach" this morning. She said it was "either one way or the other, and this morning it was the other". She "woke at six this morning with violent stomach ache, and again at eight". She mentioned her husband getting up and having some tea and her refusing any. She said that she "should be feeling better" and complained of having no energy and feeling "so tired". She said that she is in "constant pain" and then added, "well not constant, but it's there all the time, if I breath deeply or hiccup". I said that this must be most tiring for her and she said that she'd talk to A [DCL] about it.

The patient, being unsure of the researcher's role in day care initiated medical talk with her. However, the researcher did not give advice or seek a solution to the patient's problems, instead gave an empathetic response to the patient's complaints. The patient's immediate reaction was to seek another person, a nurse, to talk to. A nurse would respond 'appropriately' to the patient's medical talk; seek a solution to the patient's problems, and give advice.

Advice frequently given in day care concerns patients' diet. Dietary advice often accompanies blood sugar testing, and is mainly aimed at patients with diabetes, as is illustrated in extract 24 and the following:

> Extract 28: Field notes ST13-2 lines 44-54
>
> [ ] I asked whether Br [PT] could have biscuits because she is diabetic and E [CA] got out some 'nice' ones saying that they were better. I explained that to Br as I'd put a pile of more exciting biscuits on the table near W [PT]. E came out of the kitchen and repeated what I had said to Br and said that she could have a chocolate biscuit, "a treat" this afternoon [ ]

Dietary advice tends to involve the nurse instructing patients as to what they can and cannot eat. At home the patient is responsible for deciding for him/herself what can and cannot be consumed, but in day care, the nurses generally dictate what sugary foods are to be eaten by patients. This inconsistency is noted by the patient in extract 24: she gained eye contact with the researcher and raised her eyebrows. Other examples of dietary 'prescription' for patients with diabetes are found in the briefing sessions at site C where the day care leader instructs the volunteers as to what patients are (not) permitted to eat:

> Extract 29: Field notes BT10-9 lines 102-108
>
> [ ] 'Pe [PT]: was sick last week. He is an "insulin controlled diabetic" so must have "plain" biscuits, and maybe he should have half a glass of sherry instead of a whole one in case it is that causing his sickness.'

Dietary advice is, on occasion, also offered for health concerns unrelated to diabetes. In the following extract, the nurse attempts to encourage a patient with a pressure sore on his sacrum to have a nutritious drink (Guinness).

> Extract 30: Field notes BF13-9 lines 238-253
>
> [ ] A [DCL] came in and sat next to D [PT]. Whilst asking what drinks were wanted by everyone, Wd [VOL] asked W [PT] what he would like and he said a lager. A asked W whether he liked Guinness: yes, and she said it had all sort of things in, then said "A Guinness for your bottom?" to which he laughed and said that he wasn't going to "stick it right up!", and he , Wd and A laughed. Wd then asked him again what he'd like and he said a lager. A said for Wd to bring a Guinness as well. Wd said "See you big bully!", and there was laughter. [ ]

Again, it is apparent that dietary 'advice' is better described as dietary prescription, as in the previous examples. Although the nurse fails to tempt the patient into having the more nutritious drink, she then instructs the volunteer to bring the patient a Guinness as well as his favoured drink, in so doing the nurse imposes her 'advice' more forcibly. Within the discursive framework of medical talk food and eating is conceptualised as ‘treatment’ rather than as a social activity.

The work conducted within day care involves the performance of medical procedures and talk about medical or bodily issues. Nurses change dressings, administer drugs, check catheter bags and do blood sugar tests. Nurses and patients talk about medical issues; the patients often describe their symptoms and treatments, and the nurses attempt to provide solutions for medical problems and give advice. The patients' and nurses' components of medical talk also contribute towards the construction of patients as passive objects of work and nurses as medical workers. The patients describe their illness, symptoms, treatment or other 'bodily' or 'medical' matter, awaiting the problem solving and advice giving of the nurse. The advice given is often prescriptive: the patients are told what to do. This expectation is a manifestation of the power relations between the patients and the nurses.

## 4.4. THE SOCIAL RELATIONS OF THE 'OUT PATIENT CLINIC'

The 'clinic' brings to the fore the role of day care in the medical management of patients with terminal disease. As such 'the clinic' has many characteristics similar to that of other medical settings. These range from the structural features of the building to the conversations held between the various participants. Another similarity the 'clinic' has with other medical settings can be seen in the social relations between the participants. Nurses are seen as 'experts' doing work and patients are the passive recipients of care.

### 4.4.1. The structural context of the clinic

The structural features of day care pertaining to the 'clinic' impose subtle forms of exclusion and segregation on the patients. This inequality places the nurse in the dominant position as medical worker and the patient as the object of medical work.

Uniforms form a prominent visual distinction between the various participants, accentuating the 'medical' role of the nurse. The segregation of participants at lunchtime further distinguishes nurses from patients; nurses eat in the staff room, away from the patients. The nurses take breaks away from their work. Consequently, lunch breaks not only segregate participants according to their 'nurse' or 'patient' status, but also position patients as the object of the nurses' work.

Like the 'staff room', certain areas of the day care building are commonly construed as 'staff territory. Staff only areas (the kitchen) are open to nurses and volunteers but not to patients, whereas patient areas (the main sitting or "waiting" room) are open to all participants. Patients are restricted to patient areas, whereas the nurses are can go where they please. Another structural feature which excludes patients is the briefing or handover. Associated with many medical settings, briefing routinely involves talk about patients, but does not involve the patients themselves. This again contributes towards the construction of the patient as the object of the nurses' (and volunteers') work.

### 4.4.2. The 'working' context of the clinic

Both nurses and patients are active in the construction of patients as 'passive recipients', and nurses as 'active experts'. The authority of the 'expert nurse' and the submission of the 'passive patient' is expected and accepted unquestioningly, and is manifest in verbal and non-verbal behaviour of patients, volunteers and nurses.

The following extract describes the arrival of a patient at day care, illustrating how the verbal and non-verbal actions of the participants serves to construct the patient as a 'passive recipient'.

> Extract 31: Field notes SM19-2 lines 48-63
>
> [ ] Sa [VOL] asked Br [PT] if she wanted to keep her hat on, and she said that she would because she had a headache. I asked if she'd taken anything for it "No, not yet. E [CA] will give me something later". E came in saying a cheery hello to Br, "Oh, you're here! Hello Br.". E then helped Sa place one blanket over Br's legs and one around her shoulders. Br's scarf was removed but she kept her hat on. I then got drinks for Br, and offered her rich tea biscuits on E's direction because they are "better for her" (Br's diabetic). [ ]

Here, all participants work together to create and perpetuate the power relations of the clinic. The patient passively allows the nurse (and volunteer) to remove her scarf and cover her with blankets without any request for it to be done, and the nurse decides what the patient is to eat.

Within the clinic environment patients expect to be 'done to', or to be told what to do:

> Extract 32: Field notes ST26-3 lines 51-55
>
> [ ] I asked W [PT] what she planned to do today and she looked surprised and laughed saying "What ever they say we do, we do it" and threw up her hands. [ ]

Although rather defiant in manner, the patient is acknowledging that patients ("we") do what "they", the nurses, tell them to do. This places nurses in a position of authority, and patients in a position of submission and compliance. In this extract, the power relations were enacted by a patient. In the following extract, describing a situation where blood was taken from the wrong patient, it is the day care leader, who contributes towards the construction of the 'passive patient'.

Extract 33: Field notes SF19-1 lines 142-156

[ ] Two women in white uniforms and red sweaters came in with yellow sharps boxes, and a box/basket of test tubes. L [DCL] greeted them by the door. One of them said that she had just "blooded" a woman in another room who had answered to the name of 'Et', but who wasn't her. The blood lady (as they were known) said that the woman didn't know that she had been misidentified. The blood lady had said nothing to the patient, even when she realised the patient was not the one she was supposed to be taking blood from. L said, "I don't suppose it matters".

Underlying the nurse's statement, "I don't suppose it matters", lies the assumption that being a patient (the woman who had been mistakenly "blooded") is to passively accept what had happened. This assumption is emphatic enough for the patient never to be informed that a mistake had been made.

Although patients are considered to be passive, they are also treated as if they are vulnerable and unable to look after themselves. In sites A and B the nurses took care to ensure that patients were never left unattended. The day care nurses often asked a volunteer or even the researcher to remain with the patients when they themselves had to leave the area. This sometimes involved extensive forward planning and re-organisation, as can be seen in the following extract:

Extract 34: Field notes STH8-2 lines 406-413

[ ] L [DCL] told me that tomorrow she is working on the ward so E [CA] is on her own, and there are no 'vollies' [volunteers]. All the day care patients will be in the sitting room so that the ward volunteers can "keep an eye". She asks me if I will do the menus.[ ]

The view that patients are unable to look after themselves is also evident by the close regulation of sugar intake by patients with diabetes. As noted in section 4.3.2, nurses restrict the amount and type of foods eaten by the patient, giving strict instructions as to what the patient is 'allowed' to eat. Despite patients being responsible for their own dietary intake at home, when in day care this responsibility, and hence the control, is handed to the nurse. Both nurses and patients expect this to be the case.

Because patients are construed as the object of the medical work conducted by the nurses, patients bodies are open and accessible to the nurse. Patients are often willing to forego their privacy so that the nurse can get on with her/his work. The following field note extract documents an event in the conservatory where a patient demonstrates to the day care leader where on her body she is uncomfortable.

> Extract 35 Field notes 2-8 lines 148-161
>
> [ ] J [PT] sat back in her chair. T [DCL] came out and J told her that her tummy was uncomfortable and that she is getting sore between her tummy and breasts and her legs where it gets hot and rubs. (J's abdomen always looks very rounded and distended, a bit like a low slung pregnancy). She feels that it is worse at the moment and lifted her t-shirt high, quite openly so that her bra and abdomen were exposed. T said that Ad [doctor] could come and have a look if it was bothering her.[ ]

This extract illustrates how the patient is willing to display parts of her body not usually shown in a 'public' place. The patient's behaviour is considered appropriate because to enable medical surveillance the nurse must have access to the patient's body.

Patients were expected to forego their right to privacy on other occasions. The following field note extract describes how a patient is approached in the lounge by the day care leader wanting the care assistant to empty his catheter bag. The care assistant was at the time working towards a National Vocational Qualification (NVQ), which involved the practising of some clinical procedures.

> Extract 36: Field notes 3-8 lines 319-330
>
> [ ] T [DCL] came into room and knelt at Bi's [PT] feet, pulling up his trouser leg. I was intrigued because I didn't hear her give any explanation but Bi wasn't disturbed. A urine bag was revealed, and T said there was some in it and that it would be as well to empty it so that M [CA] could have a go (presumably something to do with her NVQ). M and Bi then went out to the toilet with a zimmer frame. [ ]

The day care leader did not ask the patient if she could take a look at his catheter bag despite him being in a 'public' place. It is also noteworthy that the patient was given no choice as to whether or not the bag was to be emptied. As well as foregoing rights to privacy, patients are expected to relinquish their right to make their own decisions.

In the following extract, the patient again can be seen to be faced with a forced choice and to waive her right to privacy. The care assistant had forgotten to take the researcher's tape recorder into the bathroom where she was helping a patient (A). To give the care assistant (E) the recorder, the researcher (AL) knocked on the bathroom door:

Extract 37: Conversation SC21-2 lines 363-388

E: Come inside Alison. A won't mind.

AL: Oh no, it's all right, I won't.

E: [comes to door] Come in a minute A doesn't mind.

AL: Oh I can't. That's not fair.

A: Why?

AL: I feel awful.

E: She said 'why?' then.

AL: I'm interrupting your privacy.

[loud noise from mechanical hoist]

E: Well, you didn't mind Alison coming in did you?

[hoist stops]

A: No. When you are a patient y- you f-forget about privacy.

E: Oh! Well, no. No, that's what we don't forget though, actually. That's what we don't forget.

AL: I'll go outside.

E: No we don't forget that. We don't forget that here, A. Not at all. That's important actually. Right, is it [the tape recorder] on again? [laughs]

AL: See you later.

[AL leaves the room]

Here the nurse invites the researcher into the bathroom where a patient is taking a bath. Without asking the patient, the nurse states twice that the patient won't mind the researcher coming into the bathroom ("Come inside Alison A won't mind", and "Come in a minute A doesn't mind"). Only *after* the researcher's entry into the room does the nurse ask the patient the leading question, "You didn't mind Alison coming in did you?". The patient is faced with a forced choice making it unlikely she will respond negatively. Despite the nurse and patients' apparent comfort with the situation, the researcher is uneasy and attempts to resist entry into the room, giving a reason: it is an interruption to the patient's privacy. The patient then explains, in an attempt to reassure the researcher, that she doesn't expect privacy because of her 'patient' status ("When you are a patient you forget about privacy"). The nurse then repeatedly and vehemently denies that this is the case, maintaining that privacy is not forgotten. This denial is despite the obvious and uncomfortable contradiction between what the nurse has said and done. The nurse's discomfort with the situation is reflected by the concluding remark and change of subject ("Right is it on again?"), as well as her laughter.

From these examples it can be seen that within the discursive environment of the 'clinic', patients are construed as passive recipients of care. The 'patient' is the object of the nurses' work and, as such, is 'done to'. He/she is not responsible for making decisions, or for taking care of him/herself, and foregoes rights to privacy. The 'nurse' is constructed as the 'medical expert', carrying out the work of the clinic; performing procedures and giving advice. The relationship between nurses and patients can be described as authoritarian, whereby the nurse has authority and power. As a result, the patient, with limited rights is subjected to segregation and exclusion. These expectations influence action: both patients and nurses behave according to the power relations of the 'clinic' environment.

Tensions are created when one or other participant does not behave according to the dictums of the prevailing discursive environment. A patient in site C expected the day care leader to take up the position of the 'medical expert' by closely monitoring her diabetic condition and giving dietary advice. The nurse does not take this responsibility, explicitly stating that it is for the patient to decide what to eat.

> Extract 38: Field notes BF9-8 lines 129-135
>
> [ ] D [PT] asked A [DCL] if she was going to test her blood today. A said not and then added "How many times have I got to tell you? You can eat what you want, there's no need any more" in an exaggerated 'telling off' way. [ ]

The day care leader behaves contrary to the expectations within the clinic discourse. By refusing to test the patients blood sugar level and telling the patient to eat what she wants, the nurse is working against the construction of the passive patient. The patient is construed as an active participant, taking responsibility for him/herself.

The nurse often voiced her disapproval of the patient's requests for diabetic monitoring, refusing to test her blood sugar levels and putting the onus on the patient to decide what was to be eaten. The patient eventually stopped expecting the nurse to take responsibility, and decided for herself what she could and could not eat, as could be seen some weeks later, when the patient's blood sugar level was tested again:

Extract 39: Field notes BF20-9 lines 142-149

> [ ] A [DCL] came over to D [PT] and tested her blood sugar level. D took and began to eat a wafer biscuit (non-diabetic) and A called out "Six" as the result of the test, and D said it was "a bit high". A said it was alright and D said she was going to eat the biscuit anyway.[ ]

Despite saying that her sugar level was "a bit high", the patient took it upon herself to eat the biscuit, without consulting the nurse. Instead of deferring to the nurse, the patient is somewhat defiant, making a 'medical' decision for herself. Both the patient and the nurse are no longer behaving according to the clinical discourse.

## 4.5. SUMMARY

Day care as an 'out patient clinic' is a specialised unit for the monitoring and palliation of patients' symptoms. Certain aspects of the structural organisation of day care contribute towards the construction of this environment. Uniforms, shifts, appointments, waiting rooms and briefings, are all aspects of the day care context pertaining to such a medical setting. Similarly, some of the work conducted in day care serves to fulfil the goal of medical surveillance, and contributes towards the construction of a clinical environment. The performance of medical procedures like blood testing, catheter care, dressing changes and drug administration, as well as talk about aspects of the body, health and illness, are all elements of the work of the 'out patient clinic'. Together with the structural features, the work of the 'clinic' defines the social relations amongst the various participants in day care. Nurses and other health professionals hold the dominant position. They are the 'specialists' or 'experts'. They are active, doing the work of the clinic; performing medical procedures on, and giving advise to patients. Patients, being 'done to', take up the subordinate position. They are considered submissive and compliant, and as passive recipients, they are the objects of care.

# 5. THE 'SOCIAL CLUB'

The discursive environment of the 'social club' draws upon discourses concerning friendship and entertainment. Within this framework, day care is about having fun; a laugh and a chat in a relaxed and informal setting. In contrast to the 'outpatient clinic', the relationship between the participants in the 'social club' is based on mutuality and as such can be considered egalitarian. As with all the discursive environments outlined, material and discursive features serve to construct day care as a 'social club'. Structural features such as architecture, furniture layout, routine and dress, together with the events, or the 'work' of the social club serve to make day care an informal and entertaining environment in which friends can be made.

## 5.1. THE 'FUN' OF HOSPICE DAY CARE

Leaflets, displays and posters publicising site C, explicitly construct day care as a 'social club' to attract new participants. In the following field note extract, the day care leader talks about a new leaflet:

> Extract 1: Field notes BF12-7 lines 234-243
>
> [ ] She [DCL] described how hard it has been designing an appropriate leaflet so that they give the right messages reflecting the "ethos" of the unit. She said that she wanted people to realise that it was somewhere to "come and have fun" and to get away from it all. She said that the leaflet has got cartoons in it drawn by K [VOL]. [ ]

The leaflet the day care leader refers to in this extract has three humorous cartoons illustrating the text entitled, "art and craft", "fun and music", and "outings". Overall the text is minimal answering the questions "What is day care?" and "How will your day be spent?". Bullet points list what day care offers ("company", "friendship", "support and advice", "new interests", "therapies" and "activities"), outlines the daily agenda, and lists the activities and services offered. The use of the cartoons, and the day care leader's emphasis on them in discussion with the researcher, conveys the idea that day care is somewhere to be sociable and have fun..

The next extract describes a wall display in the hospice reception area. It depicts day care as a place of fun:

Extract 2: Field notes BF12-7 lines 316-335

[ ] There is a pin board in the hospice reception area. On it has been arranged under "DAY CARE" lots of photos arranged around theme days they've had, eg. St. Patrick's day, St. George's day, Australia day. Each one had a leaflet describing the agenda for the day. The St. George's one read: 10.00am Arrive at [hospice]. Welcome, coffee and chat. 10.30 Activities as usual.....and seasonal dragon-baiting!!! Next to this was a cartoon picture with "Wot! No dragon!" quote. Menu: Paul's Special English Soup. Dragon & Mushroom Pie. (Fish Alternative) Bread & Butter Pudding. At the centre of the display were four bullet points: "Friendship, Fun, Interest, Support"[ ]

This display outlines 'theme' days, which are events organised by staff and volunteers. Akin to theme parties, a day is spent celebrating the specified theme. Each theme day is celebrated in a 'party' style: participants dress up, eat associated food, make associated items, have discussions and become involved in the theme in any way they can. As with the leaflet, the content and the style of the display is humorous. The menu, and the "dragon baiting", referring to the ongoing and frequent attempts by patients and volunteers to tease the day care leader, are both jokes, and the incorporation of a cartoon is entertaining. By mentioning the "welcome, coffee and chat", this activity gains importance over the many other activities undertaken in day care. Consequently, despite the listing of the four aims of day care, the message conveyed by the text as a whole is that day care is for "friendship", and more importantly, "fun".

A poster was put up in the hospice a few weeks after the display in an attempt to publicise day care to hospice users. Once again, both it's content and style is humorous.

Extract 3: Field notes BT30-7 lines 13-29

[ ] On the wall with day care information in the reception area of the hospice is a poster advertising day care. It is written in large cartoon style 'bubble' overlapping writing of all colours. In the top right corner is a cartoon face of an elderly man (he is bald) with a startled, 'spaced out' sort of expression. Amongst the writing are coloured balloons. The poster reads: " Have you considered toddling along to Day Care? [day care is written in larger letters] Laughter, friends, activities, outings. Ask for details - do it...now!

The "bubble" style of the writing, the use of cartoons, the pictures of balloons, as well as the actual words used in the poster, are designed to be entertaining and to give the impression that day care is fun and lively. The word, "toddling", is suggestive of the manner in which young children walk, and as such, could be interpreted negatively with reference to adults. However, given the humorous nature of the poster as a whole, the word "toddling" is facetious, again conveying the idea that day care is a place to have fun.

These publicity documents produced and displayed in site C, resemble party invitations. The style of presentation, as well as the content emphasising fun, laughter and friendship, serve to construct day care as a social club: somewhere to be entertained and to meet people. This construction of day care is reflected not only in the texts produced by the hospice staff; patients are also active in the process. It was a patient who first introduced the term now used to encompass this discursive environment:

Extract 4: Patient interview PL-24-9 lines 1023-1045

PI: [ ] I'd say it's like a small social club. That's about the nearest I think I can get to it. A place we can all meet and have a joke, have a laugh, and we talk about the week-end and what they did [ ]

Another patient also alludes to the idea of day care as a 'club':

Extract 5: Patient interview MA-8-10 lines 119-130

AL: What did you expect from day care before you came?

MA: I don't know what I expected. I had absolutely no idea what to expect at all. I didn't have any preconceptions. I was just very, very subtly surprised. I couldn't believe it. I'm not the sort of person who joins these clubs normally like that I don't- no it's different. [ ]

The patient construes day care to be some form of 'club', all-be-it 'different'. It is interesting that the patient denies any preconceived ideas of day care, and yet is surprised by what she found. This surprise suggests what is found is unexpected; day care differs from the patient's pre-existing concept of day care. Hence, the patient's idea of day care as a 'club' would normally have prevented her from attending. Later in the same interview the patient emphasises the friendliness of the hospice and it's role in cheering up the patients:

Extract 6: Patient interview MA-8-10 lines 521-531

AL: So has your idea about 'what is a hospice' changed, having come in?

MA: Yes I would say quite a bit, you know. A lot more sort of friendly and not-not so much of the death, rather having- you know just much more different to what I thought. People sort of cheer you up a lot. So while you're feeling miserable they cheered you up and they do their best to make you feel better.

Consistent with the idea of a 'social club', patients frequently talked of day care as somewhere to have a chat, a laugh, or to simply be in the company of others. For example:

Extract 7: Field notes BT30-7 lines 424-428

[ ] MA [PT] said that her husband has a good sense of humour and that it make's things easier. She said that that's what day care is all about, having a laugh and companionship [ ]

Extract 8: Patient interview PL-24-9 lines 937-952

PI: [day care offers] a chance to, I suppose, to meet other people, and to converse with them and have a laugh. I think we all cheer each other up, you know. Things like that.[ ]

Day care is considered to provide for patients fun and social contact that is difficult to obtain at home.

Extract 9: Care assistant interview E-10-4 lines 327-353

E: I mean most of our patients, as you know, they really do enjoy coming, I mean, look at yesterday, y'know. I mean, Jo [PT] said to me [ ] "I have really enjoyed today", she said, "it's been really nice. It's been really cheerful. We've had a lot of laughs", which, lets face it, at home they probably don't get.[ ]

As a 'social club', day care provides a distraction for patients:

Extract 10: Day care leader interview L-11-4 lines 145-151

L: [ ] I think day care, in my- here we try to make it as much fun as possible, and I always say if I've stopped my patients thinking or worrying about their cancer for two minutes of the day I've done a good job. [ ]

Extract 11: Care assistant interview E-10-4 lines 993-1022

E: [ ] I think they [the patients] enjoy the company. To have a laugh to, talk about things other than their illness. To know that L [day care leader] and I are there, and will listen to them, you know, they can get a sympathetic ear. And, as I said, I think really, I think that the best thing of all for them actually is the change of scene from sitting at home and brooding and thinking of, like them-, you know, themselves, or you know. [ ]

Common to many of these constructions, is the assumption that the purpose of day care is to cheer up the patient. The distraction provided by, and the pleasure inherent within fun and friendship, all serve to raise the patient's spirits.

## 5.2. THE STRUCTURE OF THE 'SOCIAL CLUB'

Organisational aspects of the day care context which lend themselves to the construction of the discursive environment of the 'social club' involve the allocation of time, space and staff to entertainment and social intercourse. Room use, furniture layout and décor, daily routines, as well as the garments worn by participants all contribute towards the ambience of a 'social club'.

### 5.2.1 The Sitting Room: The heart of Day Care

In all three sites, the sitting room is the spatial focal point of day care. It is the largest room and is conveniently located close to the other day care areas. The sitting room is where participants congregate in the morning and afternoon to sit and talk amongst themselves. The room is used as a base to which all participants return in between activities. In all three instances the sitting room has coffee tables interspersed amongst comfortable high-backed chairs arranged in a circle. Although the size of the circle varies from site to site, the layout of the chairs is informal and as such facilitates social interchange. As well as the location and layout of the sitting room, the carpet, curtains and general décor also contribute towards the creation of a pleasant, comfortable setting, conducive to conversation.

### 5.2.2. Informal Dress

Unlike the nurses in sites A and B, neither the day care leader nor the care assistant in site C, wear nursing uniforms. Their 'everyday' garments are indistinguishable from those worn by the patients. It is noteworthy that on day trips out, the nurses and volunteers from all the sites wear their 'everyday' clothes. This similarity in dress promotes familiarity, breaking nurse - patient barriers and, in site C, contributes towards the informality of the day care setting. The fun, cartoon style badges worn by every day care participant in site C also works to this effect.

Although in all sites tabards were usually worn by the volunteers, the volunteers in site C were very willing to remove them when the temperature in day care rose. In the other sites, tabards were never removed unless accompanying patients out of the hospice for other than medical purposes, whatever the weather or temperature. It is possible the casual dress of the nurses in site C encouraged the volunteers too to remove their 'uniforms'.

### 5.2.3. Morning Coffee and Afternoon Tea

In all sites, time was allocated each day to allow patients, volunteer and nurses to gather and converse, in a relaxed and informal setting. At the beginning of each day, the participants greet each other and congregate in the sitting room with a drink and biscuit. Described in site C as "Welcome, coffee and chat" (see excerpt 2.) this time is recognised to be an occasion for socialising. In site C this time is a formally recognised part of the daily schedule, being of half-hour duration before activities commence. Although the daily agenda in sites A and B are rarely articulated, the morning coffee session is a regular and accepted part of the day, where patients, nurses and volunteers socialise.

Similarly, at the end of the day, time is set aside once again to allow participants to gather together. In sites A and C everyone congregates in the sitting room for afternoon tea and cakes. In site B, the session is less planned, but nurses and patients gather in the sitting room for a drink and to talk. As is discussed later in the chapter, time is put aside for entertainment, as well as for socialising.

### 5.2.4. Noise, Music and Alcohol

At times when participants are gathered together, the sound of many people talking generally raises the level of noise, and the use of background music, serves to augment the 'social events or, what is done in day care which contributes towards the construction of this discursive environment.

## 5.3. THE WORK OF THE 'SOCIAL CLUB'

The actions of the patients, nurses and volunteers pertaining to day care as a 'social club', concern having fun and meeting other people. This social 'work' is carried out by all parties and involves both formal and informal entertainment. Formal entertainment refers to events that require a degree of forward planning and organisation, whereas informal entertainment is spontaneous amusement, occurring within, but not necessarily because of, an event or activity.

### 5.3.1. Formal entertainment

Staff in all three sites organise events to provide entertainment and to facilitate social enjoyment. Events include outings, concerts, quizzes, raffles, theme days, and birthday celebrations. Outings include trips to fruit farms and the houses of staff and volunteers, Christmas shopping, and visits to country parks, gardens and public houses. Concerts are provided by outside entertainers visiting the hospice; school plays, music, singing and comedy acts. As already mentioned, in site C theme days are organised in which specific subjects, usually nations, are celebrated.

The following extract, taken from field notes written after a briefing session in site C, outlines two formal events arranged for that day.

> Extract 14: Field notes BT22-10 lines 87-96)
>
> [ ] A [DCL] then said that this afternoon there is to be a "secret cabaret". Mc's [PT] sister who does cabaret had asked if she could do one at the hospice and everything had been rearranged at short notice to allow this to take place. It was not to be disclosed to Mc. Also it was E's [PT] 84th birthday yesterday so there was to be a cake for her [ ]

As alluded to in this example, the nurses and volunteers are responsible for the planning, organisation and sometimes the execution of these events. Even when not the official entertainers, some members of the day care staff become actively involved in the performance:

Extract 15: Field notes BT22-10 lines 402-418

[ ] At sing-a-longs the singer got Dy [volunteer co-ordinator], A [DCL], CJ and even Du [VOLs] to join in as the "Vernon sisters" backing singers, clapping dancing, swaying and do-whapping! There was much merriment amongst them and most of the patients grinned, smiled, clapped, and sang. Tea was served whilst the cabaret went on. There was some banter between A and D [PT] as they ridiculed each other's singing. D said to the singer that she hadn't seen anything yet, she should wait till later when A gets out her whips. This is a common joke made by D implying jokingly that A is a task-master and slave driver. [ ]

The planned outings away from the hospice, whilst not requiring an 'entertainer', are occasions designed to be fun and to promote social contact. Participants from site A and C travel to their destinations by mini-bus. These journeys are accompanied by singing, joke telling, teasing and laughter. Many of the places frequented are those designed for social activities: pubs, restaurants, and participants' homes. Even when visiting places not readily classified as 'social' settings (such as gardens or fruit farms), the participants remained together, talking, laughing and joking.

The talking, laughing and joking that accompany many of the formal entertainment, is the main constituent of what is termed here, 'informal' entertainment.

## 5.3.2. Informal entertainment

Patients, nurses and volunteers all gained amusement from activities that did not require planning and organisation. Although not planned, these activities can be considered intentional; they are carried out in order to provide amusement. The nurses and volunteers see it as part of their role to liven up day care, to make it a fun place to be. In Extract 16, a volunteer describes how a team feeling is promoted and patients are "drawn out" of themselves when in site C day care.

Extract 16: Volunteer interview K-18-10 lines 10-77

K: I think A [DCL] is the key figure in this. Herself, her personality, the way she runs the whole show. When she was away- [ ] there is- that sort of- vital, vitality was missing, because of-which is A, and I think that's what holds it together. Briefing, okay we hear about the patients, to me that's neither here nor there, but it's just being together there, and the talking that goes on. I think A in herself- we sort of spark one another off, purposely. You know, we're very insulting to one another, and I think this sometimes shocks people until they know us. But it stimulates a lively, free, happy atmosphere. So I think that is the answer, you know, her personality for starters which engenders the rest, you know the knock about comedy from start to finish.

AL: Yeah, yes. It's like being in a 'Carry On' film!

K: [laughs] Yeah! [laughs] And of course, now and again you get a prize patient like D, who is just, just beautiful, a good set up person, you know. [ ] And it draws all the others out, like Mk [PT], you know. I mean he's been drawn out hasn't he. [ ] Pl [PT] is naturally cheeky, can take a lot of joking, but you do get, occasionally, someone who's very quiet and sheepish, which is understandable [ ] But then, you know, see the idiots we are and start [laughs] start joining in!

Within this extract, the volunteer's use of words is particularly interesting: he refers to day care as the "whole show", and talks about the "knock about comedy" that occurs. Such metaphorical language refers back to the theme of entertainment in hospice day care and contributes towards the construction of the 'social club'.

Within the 'social club', patients tend not to talk about their illness or related problems. Rather, they talk about holidays and shopping or other 'safe', or 'superficial' topics. As such talk functions to be sociable, to make friends, and to have fun. Much of the informal entertainment is achieved through such friendly and fun talk, or what is here termed, 'banter'. Informal entertainment is also provided by non-verbal means. Subtle behaviours such as eye movements or facial expression, as well as more flagrant bodily actions, convey a great deal of humour

### 5.3.2.1. Banter

Banter involves jokes, sarcasm and innuendo. Much of the humour of the 'social club' is ingrained in the bantering amongst the participants. Jokes and innuendo are often implicit, enmeshed within the structure of the talk. The ongoing, or 'rolling', nature of conversation often prohibits the extraction of discrete portions of humour. For this reason examples of banter in day care are extensive, but this length is necessary in order to capture the humour of the talk.

The following field note extract describes part of the conversation accompanying a group physiotherapy session, led by the physiotherapist in site C.

> Extract 17: Field notes BF19-7 lines 206-250
>
> Ny [PHYSIO] was wearing a dress this morning and commented on this when showing the patients a leg exercise which involved raising one leg up the other. A [DCL] called from behind W's [PT] chair "We don't want to see your knickers Ny [PHYSIO]!" to which D [PT] added "She doesn't wear any!" and the laughter began. Dn [VOL] then added that Ny wasn't wearing a red hat. I asked Ps [VOL] if this was part of a saying. The saying was 'red hat, no draws', she hadn't heard it for years. JS [VOL] made comments about the tone of talk going on saying "It'll be X-rated soon!". Ny then went on to guide the patients through "bum" exercises. JS and A exclaimed mock shock at the use of the word. Ny explained why the exercises were good and A added "you should be able to pick up a five pound note between your buttocks" and D, to the encouragement and jeering of other patients, said that she'd do it if A was willing to pay. Wd [VOL] counted up the number of people in the room and said that A must bring in a hundred pounds. A retorted "You'll do anything for a fiver, you lot. [ ] After the physiotherapy Ny asked who would like some "smelly massage" today. All the patients except Nt put up their hands. Ny said that the volunteers should "gently feed them in" to the therapy room one by room. A called out "We don't feed them gently, we throw them up!".

During the physiotherapy session, the day care leader, volunteers, and patients join in the banter. The initial joke, made by the day care leader is directed at the physiotherapist ("We don't want to see your knickers"). The joke is then carried on by a patient,("She doesn't wear any!") and then by a volunteer referring to a saying about hats and draws (knickers). Another volunteer then scolds everyone in jest for lowering the tone of the conversation. Continuing from this, the day care leader and the volunteer react with amusement at the physiotherapist's use of the word "bum", and then the day care leader provides an amusing interpretation of the physiotherapist's explanation for the exercise ("you should be able to pick up a five pound note between your buttocks"). There follows a jocular interchange between the day care leader and a patient about payment . At the end of the physiotherapy session the physiotherapist asks who would like aromatherapy, and requests for the patients to be brought to her one at a time ("gently feed them in"). Referring to the patients, the day care leader concludes the conversation with a play on words ("we don't feed them gently, we throw them up!"), altering the meaning first ascribed to the word 'feed' by the physiotherapist.

Extract 17 illustrates the 'rolling' nature of the banter between participants in day care. The topic of the joke evolves as utterances are made by one participant, then another, and another, and so on. The extract also shows the teasing nature of the remarks that are commonly made during bantering episodes. In the following extract both a patient and the day care leader are teased.

> Extract 18: Field notes ST13-2 lines 366-389
>
> [ ] Later when everyone was back from lunch just before I left, Jo [PT] stood up, and Li [VOL] in a joking voice asked her where she was going, and added before Jo had a chance to answer, "Do you need help with your knickers?". They seemed to parody the carer - caree relationship, having fun, Jo talking about her black underwear and gently scolded Li for implying that she required help (possibly a little embarrassed because this had got the attention of everyone in the room). There were a few innuendoes about black underwear and references to 'Esquire' magazine (in which they had once found an article about penis enlargement which had been the source of much merriment). L [DCL] walked in during this and Jo covered her mouth before she and Li started teasing L about the man who is arranging her holiday using the term "toy boy" [ ]

The volunteer, makes fun of the patient, making explicit her assumption that the patient had got up to go to the toilet, with her remark "Do you need help with your knickers?". This is not a serious inquiry, rather it is a jovial acknowledgement of the relationship between herself as a volunteer helper, and the patient. The patient responds with good humour, despite her possible embarrassment at the intimacy of the question. The two of them continue the joke, talking about 'sexy' underwear and magazine article. The patient, by putting her hand over her mouth, jokingly implies that the conversation ought to stop when the day care leader enters the room. The volunteer and the patient continue to use sexual innuendo, this time to tease the day care leader. Innuendo is another feature common to much of the banter in day care. In the following extract, much of the innuendo is communicated by non-verbal means: gesture and eye contact.

Extract 19: Field notes BF6-9 lines 276-306

[ ] A [DCL] asked loudly if anyone was interested in doing creative writing. There was silence for a few seconds. She then laughed and said sarcastically that it seemed popular. For the next ten minutes or so there were jokes, banter and back chat as they discussed what creative writing was/was not and there was much innuendo about Pl's creative writing if he did any. The implication was that he would produce rude, crude, dirty or stupid odes. Pl laughed at this and said that A, W and D [PTs], and Dn [VOL] joined in, and the others listened smiling and laughing. Pl said "There was a young woman from Durham..." and raised his eyebrows at A who laughed. A then responded "I know one - there was a young woman from Leeds..." and raised her eyebrows at Pl who laughed, "...who bought a packet of seeds.." and A then looked up and away as if to indicate that was as far as she was going to go. Laughter. W [PT] made a contribution: "I'm Popeye the sailor man, and I live in a caravan!" Pl, A and he laughed loudly [ ]

In site C, much of the banter referred to the authority of the day care leader. The day care leader at different times was referred to as "the witch", "fuhrer" and as in the extract below, "Ayatollah". This field note excerpt documents the conversation held between the hospice chaplain, day care leader, and the patients, during an art and craft session.

Extract 20: Field notes BF9-8 lines 201-221

MH [VOL] came in to take drink (aperitif) orders. There were claps when she came in and a "hurrah!". MH offered to get on the table and sing. Shortly after T [Chaplain] came in saying "How's the Ayatollah?" talking to A [DCL] told him that he ought to be careful when she has scissors in her hands. K [VOL] and D [PT] then told T that next week A is away so they can relax and enjoy themselves. D said that she enjoys herself anyway despite A. T then called to A "Hey watch out! The peasants are revolting!". D repeated this and then said to K "get it? The peasants are re-volting!". There were many laughing references to ducks. I asked what was the joke and D said it was just something that T always went on about and T added "It shows God has a sense of humour!". Tthen went on to tell jokes.

Extract 20 illustrates the hospice chaplain entering into the banter of day care. The chaplain initiates the joking, focusing on the day care leader as the object of ridicule. In the following extract, the patients collude to make fun of the day care leader:

> Extract 21: Field notes Bf26-7 lines 219-233
>
> [ ] Pl [PT] asked A [DCL] if she'd get him another shandy. A got it saying that Wd [VOL] had been busy. Wd, My [PT] and Pl exchanged mock glances as if to suggest this was not the response they were expecting. A came back with his drink and then G [PT] asked if he too could have one and A fetched him one. On her return, H [PT] asked if he could have a drink, to which A responded in a loud authoritarian voice "You can get your own!" and gave him a mock tirade about him waiting until she got back to ask. Everyone laughed and H beamed.

The taking of orders, and the fetching of drinks is usually a task performed by the volunteers. The patient (Pl) has deliberately asked the day care leader for a drink, despite volunteers being present. The day care leader responds with sarcastic explanation as to why she should get the patient a drink; the volunteer had been busy. Both the patient and the volunteers exhibited some surprise, by exchanging glances, as the day care leader went to fetch the drink. The expectation was that the day care leader would ask one of the volunteers to get the drink. Patients G and H, by asking the day care leader for drinks on her return each time, continued the joke. The day care leader, realising she is the object of ridicule responds to the third request in a jocular manner, feigning anger. It is perhaps this response which everyone was expecting at the initial request for a drink. This example illustrates how even very mundane activities in day care can become situations of entertainment for all the participants.

Extracts 18, 20 and 21 depict the day care leader as the object of ridicule. Volunteers and patients are also at times the focus of amusement in day care bantering. The following extract, describing the day care leader bantering with patients and volunteers while planning a shopping trip, shows how the patients' disabilities are a source of humour.

> Extract 22: Field notes BF6-9 lines 340-355
>
> [ ] Whilst parking was being talked about A [DCL] said they wouldn't need parking because she was planning on throwing them all out without stopping. She added that she would throw out their wheelchairs as well so that they could get around! Dn [VOL] commented, "Oh, she's all heart!". Ro [VOL] then

> suggested that they could contact the police to perhaps organise parking spaces near the shops. A exclaimed "Police! we don't want to get the police involved!" in an exaggerated way. Ro added: "Why have you got something to hide?". Laughter. [ ]

In this excerpt, the day care leader uses humour which could be regarded as 'bad taste'; she teases the patients, saying that she will throw them, and their wheelchairs, out of the moving mini-bus so as to avoid having to park. The patients' disabilities are part of the joke. The joke however is accepted as just that, acknowledged by the volunteer sarcastically saying "Oh she's all heart!". The joke then turns on the day care leader when the police become involved as the topic of conversation.

The following extract describes the behaviour of the day care leader towards a volunteer. It is the volunteer who becomes the focus of fun.

> Extract 23: Field notes BT6-8 lines 189-200
>
> [ ] A [DCL] left the meeting whilst it continued and came into the therapy room. She put some music onto the tape recorder and swayed her hips humming. Pl joked with her and she said she was introducing a bit of culture to the group. She then went away again. A came in and went out a few times, each time kicking K [VOL] playfully as she passed. He acted passively with mock resignation. [ ]

The volunteer plays the role of the 'stooge' in a double-act performed to entertain the patients. This excerpt also illustrates a further aspect of the informal entertainment in day care. It is not so much *verbal* banter that provides the amusement; rather it is the *non-verbal* activity; the playful kicking and the expression of resignation, which make the episode funny.

### 5.3.2.2. Non-verbal Banter

Although often accompanying verbal banter, the non-verbal actions of the participants also provide entertainment. The humorous nature of a non-verbal action is illustrated in the field note extract below, which describes the end of a group physiotherapy session in site C. The participants had been using sponge-like objects called "squidgys" for hand exercises.

Extract 24: Field notes BF6-9 lines 177-197

[ ] There followed the usual laughter and praising comments as the exercises were carried out. A [DCL] suddenly said "Here comes trouble up the drive!" adding "don't anyone mention ducks!". I therefore presumed it to be the arrival of the chaplain who for some reason always talks about ducks when with the patients. Pl said that they should shout "duck!" and throw the squidgys at him - laughter. Near the end of the session, Ny [PHYSIO] had everyone throw their squidgy to their neighbour. At the very end she said that we were to put the squidgy's in the bag and she held open a plastic bag and was about to circulate the room when squidgy's were thrown at her/the bag – Laughter.

It can be seen that the behaviour of the patients, throwing the squidgys at the physiotherapist, is amusing. This illustrates how 'formal' activities like physiotherapy, designed for purposes other than entertainment, are made to be entertaining through the action of the participants. It can be seen in extract 25 that the 'formal' activity of having a meal is lightened and made entertaining by the behaviour of a patient:

Extract 25: Field notes 6-7 lines 316-325

[ ] Pe [VOL] came in saying the lunches were ready.(12.20). I sat with my back to the kitchen, D [PT] sat to my left facing the entrance corridor, A [PT] sat opposite and over a place, and Bi [PT] was helped by M [CA] into the chair to the right of me on the table. D started singing a western song and pretended to strum a guitar. A joined in quietly, both were laughing.

The behaviour of the nurses and volunteers can also be entertaining. In the following two extracts the day care leader and the volunteers play-fight. Such behaviour may be examples of the nurses and volunteers' deliberate attempts to provide informal entertainment.

Extract 26: Field notes BF9-8 lines 266-270

A [DCL] chased El [VOL] round the table with a cold can to press on her after El was jokingly rude to her. Later on A threw a ball of cling film at El hitting her in the eye.

> Extract 27: Field notes BT6-8 lines 83-87
>
> [ ] S [VOL] came in with a plate of biscuits and dropped one. A [DCL] shouted at her and S picked up the dropped biscuit and threw it at A.

Akin to the day care leader's mention of the patients' wheelchairs in extract 22, some of the non-verbal banter relates to aspects of the body, disability or illness. For example:

> Extract 28: Field notes SW14-2 lines 162-181
>
> [ ] E [CA] came in asking me did I know that A [PT] wears a wig. A has short grey hair, rather unkempt looking. It is thicker on top than on the sides and at the top back of her head it is almost bald. I hadn't seen her wear a wig. E then asked A to get it out and she did so smiling. L [DCL] came in then and they [the nurses] looked at it saying that it was a good one, not like they'd imagined from the NHS. L then put the wig on, asking E to tuck up all her hair out of sight. When E had done this, L said that she was going over to the [in-patient] unit to "give them a laugh", and disappeared. E followed. A smiled and told me that she was told that she would lose her hair with the treatment, the radiotherapy.

Without asking, the day care leader puts on the patient's wig and goes away to the in-patient unit to give the nurses there "a laugh". The behaviour of the nurses described in this extract could be considered insensitive. However, the patient could be said to show her appreciation of the nurses' humour by smiling.

Within this discursive environment, day care is seen to be a place to meet people, to chat, laugh and joke. Structural features of the setting, together with the 'work', or events, serve to construct day care as a 'social club'. Structural features include the room layout and décor, the every-day dress of staff, the allocation of time specifically for 'social' activities, as well as the background noise. Some aspects of the 'work' in day care involve formal, or planned, entertainment such as outings, concerts and quizzes, and the informal entertainment is provided by verbal and non-verbal banter. All of these elements combine to create and sustain the 'social club'. These features also create and sustain the social relations found within this discursive environment.

## 5.4. THE SOCIAL RELATIONS OF THE 'SOCIAL CLUB'

### 5.4.1. Friends

Unlike the discursive environment of the 'out patient clinic', the 'social club' provides a relaxed and informal setting conducive to conversation, making friends and having fun. Participants come to know each other as 'friends'. In the interview extract below, a patient talks about the advantages of day care. It is significant that she uses the terms "people", and "friends", to represent day care participants, making no distinctions between patients, nurses and/or volunteers.

Extract 29: Patient interview MA-8-10 lines 986-994

MA: [ ] You've met people that you haven't met before. That's how I feel, I've met people that I would never have known. I enjoy meeting people a lot. You know having to stop work. At least I can come here and I can meet people. I make new friends you know I really do feel they are friends. [ ]

At the end of the extract, the patient's repetition of "friends", signifies that this is an important aspect of what is said, and suggests that irrespective of their role as 'nurse', 'patient', or 'volunteer', the relationships this patient has with other day care participants are based on friendship. The implicit egalitarian principle of equality inherent within 'friendship' suggests that all participants: nurses, volunteers and patients, have an active role in establishing and maintaining relationships in the 'social club'. 'Friendship' suggests mutualism and reciprocity; actions are done, or emotions are felt, by each towards the other. The mutual 'give and take' inherent in 'friendship' is evident in the use of humour whereby patients, nurses and volunteers make fun of each other. Members of each party are both the focus of ridicule, as well as the humorist.

Aspects of day care which lead to the identification of 'nurse', 'patient' or 'volunteer' signify that the participant's formal role is more significant than his/her role as personal 'friend'. Features pertaining to the formal roles draw attention to the differences between the participants. Removing or reducing ways in which the various participants are distinct from each other promotes a sense of similarity and equality, and facilitates the formation of friendships. The everyday clothes worn by the nurses in site C, as well as making them similar in appearance to patients, also makes them more familiar and approachable. When going on outings, the nurses at sites A and B also wore everyday clothing instead of their usual uniforms. These events were explicitly organised as 'social' occasions, and to this end the use of uniforms was considered inappropriate. Everyday clothing is considered more sociable, more personal, more friendly.

The formal roles of the day care participants are also distinguished by territories, as discussed in chapter four. When the participants identify themselves primarily as 'friends', however, the territory boundaries can become less definite. Patients, as 'friends', are on an equal footing with nurses and volunteers, and as such can enter areas often considered to be for nurses and volunteers only. The following extract shows a patient entering the kitchen of site B, a room which on other occasions, is tacitly considered as 'staff only' (see section 4.2.3.).

> Extract 30: Field notes ST13-2 lines 207-217
>
> [ ] Jo [PT] then came into the kitchen with a box of sweets and she and H [VOL] started talking about their churches, with Jo repeating the story she had told earlier about her new vicar. Jo then came out of the kitchen and sat back down in the same seat as before and H sat on the large stool in front of the table under the window between Br [PT] and L [DCL]. [ ]

### 5.4.2. Entertainers and Audience

As well as playing equal roles as friends, nurses, patients and volunteers, all have active roles as entertainers and audience. Although not necessitating an 'entertainer', much of the in-house entertainment require nurses, volunteers and/or patients to 'perform'. Birthday celebrations need someone to sing the song "Happy Birthday To You", raffles need a caller, theme days need someone to dress up, and quizzes need quiz-masters. The nurses and volunteers are not the only participants active in such roles.

The patients join in with the singing, answer questions and dress up. Within the informal entertainment of the verbal and non-verbal banter, patients also play active roles as entertainers. The following field note excerpt describes a bantering conversation following a games session. A patient (P1) can be seen to be the main entertainer, making jokes, using innuendo and teasing the day care leader:

> Extract 31: Field notes BF12-7 lines 337-355
>
> [ ] As tea was served with all patients back in the sitting room, A [DCL] wrote out the answers to the puzzles on the white board. Pl [PT] and El [VOL] poked fun saying that it would be easier if she read out the answers because no one can

> read them anyway. She was only copying them from the book because she can't actually read. PI asked what was first prize. A said she'd give the winner a kiss. She, PI, EI and W [PT] then joked that the second prize would be two kisses! PI then asked EI to get him a rubber (implying that he didn't want to win). He also asked if the kiss would be a "frenchie", and EI scolded him jokingly about lowering the tone.

All parties contribute to the conversation, talking and/or listening. Those talking are involved in the conversation, and those not talking are listening, and responding with smiles and laughter. Patients are also involved in non-verbal banter: waving walking sticks, and throwing objects. As such, patients, as much as volunteers and staff, are assumed to be *active* participants in the 'work', or events, of day care.

## 5.5. SUMMARY

Day care as a 'social club' is a place to meet people, make friends and have fun. Structural features of the day care setting and the events during the day combine to construct this discursive environment. The grouping of chairs in the sitting room, or 'heart', of day care, the informal dress, morning coffee and afternoon tea, the general noise and use of music and alcohol are all aspects of the day care context pertaining to such a social setting. Similarly the formal and informal entertainment in day care serve to fulfil the goal of having fun and meeting people, and contributes towards the construction of the 'social club'. Quizzes, concerts, outings and theme days as well as conversational banter and playful behaviour are all part of the entertainment or 'fun' of day care. Together with the structural features, the entertainment events define the social relations between the participants in day care. The formal roles 'nurse', 'patient', and 'volunteer' are secondary to the role of 'friend'. Such friendship relationships are based on equality, mutuality and reciprocity. Patients are considered active, not only in their role as 'friend' but also 'entertainer' and 'audience' within the day care setting.

# 6. THE 'CARE HOME'

Within the discursive environment of the 'care home', day care provides a comfortable, 'homely' setting in which 'care' can be given. Features of the day care setting pertaining to this discursive environment include the layout of furniture, the facilities for, and daily scheduling of bathing, feeding and listening to patients, as well as the provision of 'luxury' treatments. The staff is concerned with helping and supporting patients; attending to their physical, psychological and spiritual needs. As well as caring for the patients' *needs*, the staff also attempt to provide for the patients' *wants*. Such 'pampering' is considered to make the patients feel 'special'. The staff *give*, and the patients gratefully *receive*, this special care. Consequently, patients are considered to be 'passive recipients'. However, in addition to being portrayed as passive, patients in the 'care home' are considered child-like dependants. 'Difficult' patients, those who do not conform to the mores of the 'care home' environment, do not gratefully and passively accept the attentive care they receive.

## 6.1. DAY CARE AS A 'HOME' FOR 'CARE'

When describing day care, participants commonly used metaphors to do with 'home', emphasising the 'care' that is delivered to patients.

### 6.1.1. 'Home'

'Home' is commonly used to describe day care. Both patients and staff construct day care as a comfortable, friendly place, where there are kind people to attend to the patients' needs.

Extract 1: Day care leader interview L-11-4 lines 169-178

L: [ ] I think with day care we try and make it their second home so that they feel comfortable here. They can talk, and we can give them all the other things that we've got on offer [ ]

Extract 2: Patient interview D-1-10 lines 848-881

AL: [ ] the term "hospice", now what sort of image does it conjure up for you?

D: Oh it conjures up a lovely image now, beautiful image of lovely times that I've had here. Everybody's so nice and kind and good, and I have a lovely meal while I'm up here and, as I say, everybody's here just to do everything that they possibly can for you which they do. It conjures up more or less a home from home, you know something that you would- apart from the treatments that you get- that you would do if you were at home. You know, same kind of thing. You could class it as another home from home. [ ] All in all, as I say, it's more or less like a second home. That's how I can describe it, as a second home [ ]

These participants indicate that a 'homely' environment is not so much a result of the physical setting of day care, rather it is a consequence of the actions of the staff. In order to make them feel comfortable, the staff attends to the patients' needs, they let the patients talk, they provide meals, and "do everything that they possibly can".

In the following interview extract, a patient refers to the actions of the staff in the construction of a "homely' environment. Compared to her stay in a hospital, the patient talks about being made to feel at home in the hospice as a whole.

Extract 3: Patient interview MA-8-10 lines 467-491

AL: How did you feel about the referral [to the hospice]?

MA: I was so grate- I felt so ill that I didn't mind. I was, you know, 'hospice', you think, I said, "Yes please" you know. She [a nurse] said, well I know that they could make me feel better, and "you'll get this blood and you should feel a lot better then", and it did. And, I mean I came in and they were so kind, they were so lovely. The nurses were all just like friends really, They would come and chat to you and you know, just make you feel much, much better. And the thing is, your friends could come in any time, and they'd make them feel at home. They always offer them a cup of tea, whereas, you go in the hospital they've clamped down haven't they. Your friends can't really feel at home. [ ]

### 6.1.2. 'Family'

Consistent with the notion of day care as a 'home', 'family' metaphors were attributed to the day care participants. For example, the care assistant in site A referred to planned outings away from the hospice as "family days" (section 4.2.5, extract 11). In the following extract a patient refers to the 'family' in day care whilst talking in an interview about what day care offers:

Extract 4: Patient interview JO-26-3 lines 1262-1292

Jo: [ ] but it's wonderful. There's companionship, I mean, you know, and a warm feeling of being together. Sometimes I've- but it can make you a little bit selfish. When we suddenly get- I'll find somebody else in on a Tuesday. You know, I'm pleased to see them, really like them, but I think, "You don't belong with us do you?", which is dreadful feeling. As a Christian I shouldn't feel like that, but you see, I've got it like a little family [ ]

Extending the use of the 'family' metaphor, participants talked of 'mother-figures' in day care:

Extract 5: Day care leader interview L-11-4 lines 1640-1653

L: [ ] one particular patient she almost- although she was quite ill herself, she was a substitute mother to everybody and she always asked-

AL: Was that R? [a patient who had since died]

L: Yeah. She always asked how you were and, you know. [ ]

Extract 6: Day care leader A-25-10 lines 455-457

A: [ ] N [PT] she was very much the queen bee of day care [ ] that was ages ago. I think D will be the same [ ]

The 'mother-figures' referred to in these extracts are both female patients who are older and more outspoken then many of the day care patients. A 'mother-figure' could also be identified in site A. She too was female, older and relatively outspoken. These patients often sat at the 'head' of the dining table, introduced themselves to new patients, and talked back to members of staff, and liased between fellow patients and staff.

### 6.1.3. 'Caring'

As is alluded to in extracts one and two, the actions of the staff, or the 'care' they give, are closely linked with the construction of a 'homely' environment. 'Care' is what is 'done' in day care. With this in mind, when talking about the appropriateness of the terms 'day centre' and 'day care', this care assistant chose to emphasise day care:

Extract 7: Care assistant interview E-10-4 lines 676-728

E: I tend to say 'day care' because I feel we do care for them. Because if- when I answer the phone I usually say, "Oh, day c-", you know, "day care, this is day care", you know. I think L [DCL] does as well actually. So I tend to say that – I tend to think of 'day care' because I tend to think of the care that we do, actually. You know, care for them. [ ] I mean that 'centre' just sounds too much like, I don't know, a shopping centre or [laughter] You know, I think 'day care' is much more appropriate really [ ]

At the same time, the day care leader has an opposing view to that of the care assistant, preferring to make use of euphemisms. When talking with the researcher, the day care leader explained why she wanted 'hospice day care' to be given another name.

Extract 8: Field notes SW7-2 lines 20-45

[ ] We started chatting about "day care ". Before the new centre was built (and L [DCL] had some say on it's design, e.g. the bay window was her request), L had said to "everyone" that she didn't want it called a "day centre". She said that everyone agreed at the time. She would rather call it the "[name] centre". "Day care" to her conjures up "lots of little old ladies sitting around basket weaving. You know, geriatrics". The Day Care Leaders Association, however, think that hospice day care should be called just that. L objects to both the "hospice" term and and the "day care" term, day care for reasons already cited, hospice because it can "make people afraid". [Name] is a well-known consultant physician at the hospital who is known for his kindness. L said that "to the lay person out there [name] means something different from 'hospice day care'". [ ]

To this day care leader 'day care' conjures up a negative stereotype to do with "geriatrics", and "basket weaving". It is a pervasive view; nurses in all three sites of study caution against this same stereotype. In contrast to the day care leader cited above, the care assistant in site A associated the stereotype with the term 'centre', rather than 'care':

Extract 9: Field notes 9-8 lines 494-498

[ ] M [CA] mentioned day care and then said that she preferred the name 'day care' rather than 'day centre' because day centre for her conjures up a picture of a "load of old geriatrics sitting around". [ ]

The day care leader at site C frequently voiced her dislike of 'basket weaving' when planning activities for the day with volunteers and the Occupational Therapist. During her interview, the researcher queried what was the problem with basket weaving:

Extract10: Day care leader interview A-25-10 lines 202-207

AL: 'Basket weaving'. Is it the image?

A: Yes. Basket weaving is a perfectly presentable past time, but it's the image that goes with it of people sitting dribbling making these baskets. [ ]

As this extract illustrates, basket weaving is associated with disability, infirmity and old age. To counter this negative image of day care, nurses in all three sites were concerned not to allow day care to appear 'institutional' or associated only with older people. In site B the layout of the chairs was considered significant.

Extract 11: Field notes SF8-3 lines 131-140

[ ] L [DCL] then remarked on having rearranged the chairs in the sitting room [in the main hospice] so that it was "less institutional" and added that "this room [the day care sitting room] can be like that sometimes, that's why I pull out those chairs". E [CA] said that the chairs in the sitting room make the room "more friendly" and asked Br [PT] if she agreed: she did.. [ ]

On one occasion the day care leader rebuked the researcher for not altering the layout of the furniture in the sitting room:

Extract 12: Field notes ST30-1 lines 93-100

[ ]L [DCL] came in saying loudly "Oh God! Looks like geriatrics!" and scolded me ("Oh, Alison!") for not moving the chairs round into a circle. S [VOL] got out of his chair and moved it round as I moved mine into the middle of the room slightly. [ ]

Again in order to counter the negative stereotype of day care as "geriatrics", having younger patients attend day care is considered to be favourable.

Extract 13: Field notes BT24-9 lines 40-49.

[ ] CJ [VOL] said it was nice to see PI and Mc [PTs] talking at lunch last week, implying that it is good for them (both have brain tumours and are relatively young). A [DCL] said that it was 'good' that there are a number of "young" people now coming to day care. If the woman who visited last week decides to come too it would be 'good'. [ ]

Despite attempts to ensure day care is not viewed as 'little old ladies weaving baskets', it would appear that it is, on occasion, considered a service for the 'elderly'. The following field note extract describes part of a conversation between a hospice volunteer and the researcher:

Extract 14: Field notes ST20-2 lines 240-245

[ ] He [VOL] asked me what I was doing. I explained I was doing research into hospice day care. He expressed some surprise saying that "the elderly" are not a priority research area in medicine. [ ]

Drawing upon metaphors of 'home' and 'family' and the notion of 'care', day care is constructed as a 'care home'. This discursive environment is often associated with derogatory stereotypes concerned with 'geriatrics' and 'basket weaving'. Despite attempts by staff to counteract these negative constructions, day care as a 'care home' can still appear to be a service for the 'elderly' and 'infirm'. Aspects of the organisation, or structure, of day care do not necessarily counter this view.

## 6.2. THE STRUCTURE OF THE 'CARE HOME'

Some aspects of day care organisation contribute towards the generation and maintenance of a 'homely' and 'caring' atmosphere. Some of these features serve to construct the physical surroundings of a 'home' and other features enable the 'care' of the patients.

## 6.2.1. Furniture layout

As described in section 6.1.3, the layout of the furniture in day care is considered crucial as to how day care is construed. As well as ensuring that seating is arranged in groupings or circles, away from the walls, the use of bookcases and cabinets akin to those found in any home, serve to enhance a homely atmosphere. In site A, a fireplace formed the focal point of the sitting room, around which chairs were arranged. The use of coffee tables invoked informality, and the general décor of the room, resembles that of a living room in someone's home. Overall the furniture layout created a cosy and homely environment.

## 6.2.2. Resources and facilities

Several structural features pertaining to the 'care home' environment are concerned with the resources available to staff to enable them to carry out the care of the patients. The use of multicoloured crochet blankets in site B enables staff to keep patients warm as well as adding to the 'homely' atmosphere of day care. On their arrival in day care, a nurse placed these blankets over patients' knees. The nurses only gave crochet blankets to older female patients, or to those who were relatively immobile, for example:

> Extract 15: Field notes ST23-1 lines 59-63.
>
> [ ] **A new patient arrived in a wheelchair. She was assisted to the comfy chair Br [PT] had been sitting in, and a crochet blanket was put over her knees.** [ ]

Crochet blankets are commonly associated with older people (particularly women) and here it can be seen that nurses perpetuate this understanding, and by so doing, compound the stereotypical image of day care.

Other 'caring' resources concern patients bathing, feeding, resting and practising their religion. Two out of the three study sites had bathroom facilities for patients with large jacuzzi baths designed for people with limited movement and mobility. The nurses made themselves available to help patients who wanted a bath. A mid-day meal and 'home-made' foods, such as cakes and biscuits, were supplied regularly, and someone was available to assist patients who required help when eating, in all sites. Site C had a "quiet room", and in all sites footstools were provided to enable patients to rest comfortably. Aromatherapy, massage, reflexology, as well as beauty treatments were offered in varying amounts in the three units and in site C, a volunteer was specifically trained to conduct 'relaxation' classes for the patients. Clergymen visit each day care and there is a chapel built within the hospices attached to sites A and C.

### 6.2.3. Daily Schedule

Daily scheduling ensured that periods of time were allocated to specific 'caring' activities. Baths were usually conducted in the morning, and were often given priority over other activities. Lunchtime was at a set time in all three sites, and as mentioned previously in section 5.2.3, time was put aside for morning coffee and afternoon tea. Periods of rest are usually in the afternoon. In site C patients went to the "quiet room" to sleep, or for relaxation sessions, immediately after lunch. In sites A and B, no formal time or place was put aside for rest, however, patients commonly retired to the sitting room after the mid-day meal to sit quietly or sleep in their chairs. In site C the relaxation session provides patients with a time to talk as well as a time to rest. This will be discussed in section 6.3.2. In sites A and B the hospice chaplain did not visit at pre-arranged times, but tended to 'drop-in' informally to talk with patients.

The facilities for and allocation of time to bathing, feeding, resting and religious practise, do much to promote the comfort and well-being of the patients. Together with the furniture type and layout, these aspects of day care organisation serve to construct the 'care home' environment.

## 6.3. THE WORK OF THE 'CARE HOME'

As introduced in section 6.1., much of what is 'done' in day care as a 'care home' centres upon the concept of 'care'. A care assistant provides an understanding of what it means to 'care' when she talks about hospice philosophy:

Extract 16: Care assistant interview E-10-4 lines 14-45

E: [ ] well the philosophy I believe is obviously to make life as pleasant for our patients when they come to us. It means getting them out of the four walls of their own home, or giving their carers or family a little bit of respite which is important you know. And supporting them, talking to them, you know, and helping them really come to terms with their illness, and really, just well, I suppose really basically helping them as much as we can, you know [ ]

Care involves helping and supporting patients. Both the nurses and the volunteers are said (and expected) to care for the patients in day care. In the following field note extract, a patient talks to the researcher about the caring nature of the nurses:

> Extract 17: Field notes 2-8 lines 568-584
>
> [ ] I stood with Bn [PT] in the lounge area watching people going. He commented on the lovely atmosphere in day care. I asked what he thought made it that way. He said it was because the staff are "hand picked", T [DCL] and M [CA] get on so well and complement each other and they're basically very caring people. He illustrated this by describing a time when working in the garden in hot weather, M had spontaneously brought the gardeners a cool drink each. He said that, "that's the sort of care I mean. No one else would have done such a thing". [ ]

Once again it appears that the 'lovely' atmosphere of day care is a result of the caring actions of the nurses. The patients consider the volunteers to be caring as well. The following field note excerpt describes a conversation held between patients over lunch:

> Extract 18: Field notes BT30-7 lines 368-375
>
> [ ] They [the patients] all agreed that everyone is kind hearted and MA [PT] talking about the volunteers, said that although you'd expect them to be "La de da" they are extremely kindly. She said they can't help being "La de da" but they do much good [ ]

As well as setting up expectations as to the propensities of the nurses and volunteers, the 'care home' also defines who should be a 'patient'. Day care as a 'care home' is for helping and supporting the patients. Staff who view day care in this way consider it unnecessary for patients to come to day care if they do not receive 'help'. For example, the next extract is taken from an interview with a day care leader who anticipates a patient will no longer be able to attend day care after the hospice doctor reviews his condition.

> Extract 19: Day care leader interview L-11-4 lines 919-924
>
> L: [ ] he really is quite well and he's going to have a review, and although he doesn't actually know it at the moment he'll probably be discharged because we're not actually helping him any in here [ ]

### 6.3.1. Physical Care

The 'care', or help and support the patients are given can be described as physical, psychological and/or spiritual. Physical care is provided by the nurses, who help the patients bath, wash hair, shave, eat, walk and sit comfortably. Sites A and B provided bathing facilities, and in both sites the nurses gave priority to bathing over other possible activities. Bathing is considered important not only for cleanliness, but also for providing patients with a relaxing and pleasurable experience. Baths were fitted with jacuzzi apparatus, and patients were routinely left alone for a while to enjoy the bubbles. This reflects a pervasive principle underlying the actions or work of the nurses in day care as the 'care home'; 'care' is provided not only to satisfy the patients' basic needs, but also to give pleasure and comfort.

### 6.3.2. Psychological Care

Staff of day care as the 'care home' also sought to satisfy patients' spiritual and psychological needs. As mentioned above, chaplains visited day care regularly, and in site C a weekly service was held. Caring activities also involved talking. As a 'care home', day care is for patients to talk about their worries and concerns about their illness and related circumstances. In site C, these issues were mainly discussed at a specific point in the day. The following field note extract describes the day care leader talking about a new publicity leaflet for day care.

> Extract 20: Field notes BF12-7 lines 234-257
>
> [ ] She [DCL] described how hard it has been designing an appropriate leaflet so that they give the right messages reflecting the "ethos" of the unit. She said that she wanted people to realise that it was somewhere to "come and have fun" and to get away from it all. She said that the leaflet has got cartoons in it drawn by K [VOL]. She then added that although it is very much this way inclined, patients could also cry if they wish. She described two patients in recent days who have spent much of their day crying in day care, and that it's all right to do so. She said whilst having fun is one thing, there is a need to acknowledge that "these people have got real sorrows and grief". She mentioned that more serious talk, or talk voicing worries was usually done in the relaxation sessions.[ ]

In the relaxation sessions, a trained volunteer takes the patients through a relaxation exercise, then sits quietly while the patients relax or sleep. She then rouses the patients gradually, talking in a soothing tone, and asks each person in turn how they are feeling. It is at this point that patients talk about their concerns. For example, the following extract is taken from a recording of a relaxation exercise. It is nearing the end of the session and the volunteer (T) asks after the welfare of the last patient (Ek):

Extract 21: Conversation BC1-10 lines 347-372

T: How about you Ek, you're very quiet. Do you want to talk about your daughter?

[Long pause. Ek starts to weep. T goes over to Ek and speaks quietly to her]

T: I'll just help the others out, all right?

Ek: [Sobs]

T: It's all right. It's all right. It's all right. Shh. Shhhh. It's all right. There you are, it's all right. Are you finding it very hard Ek?

Ek: [Continues to sob]

[Other patients start to move out of the room. T asks a volunteer who comes to help to get A , the day care leader]

T: Do you want to talk about it?

Ek: [Sobs. Takes tissue offered by T]

[When all the other patients have gone]

T: What are you finding very hard Ek?

Ek: My daughter.

T: Your daughter. [Long pause] Is she finding it difficult to cope with you being ill?

Ek: Yeah! [Starts sobbing] She's very angry with me.

T: She's angry with you.

Ek: Yeah.

T: And how's that made you feel? [ ]

In sites A and B, no 'formal' time is allocated to such 'counselling', although in site B the nurses report that patients talk about their worries whilst bathing. In these circumstances, the patients and nurses are one-to-one, and the patient's nakedness adds to the intimacy of the situation. Such intimacy appears to facilitate serious talk, but at the same time places the participants in unequal power positions; the patient's nakedness places him or her in a position of childlike dependency (see section 6.4.3.).

In the ‘care home’, psychological support is also considered to be gained from patients. Because patients have similar diagnoses and prognoses, it is assumed that they can talk openly about their experiences:

Extract 22: Day care leader interview L-11-4 lines 220-270

AL: So do you think there are advantages for patients meeting other patients?

L: I think there's a great advantage, yeah I do.

AL: In what way?

L: Because of the isolation at home. And I often hear of patients, you know, who might have had- say, they both had breast cancer, they actually discuss their operations and things like that so they know that the other patient's been through what they've been through. And they talk about it, you know, people who- women who've lost their hair through treatment, you know, sort of chat about their wig and whatever, and what they did and what they didn't do. I just think it's a general support from staff as well as the other patients.

As well as counselling and talking about patients’ problems, psychological care in site B extended in one situation to and activity designed specifically for older people. The use of a ‘reminiscence package’ and the indifferent behaviour of the patients, however, reinforces the negative stereotype that day care is for “geriatrics”.

Extract 23: Field notes ST23-1 lines 184-220

[ ] L [DCL] came in and mentioned music. H [VOL] collected a tape recorder from the other end of the room and put it on the table between W and Br [PTs],and put on a tape describing it as a music “quiz”. Theme tunes from the 40s and 50s. This then played. A piece of music, a pause, the same piece of music then a pause and then a different piece of music repeated and so on. H had the leaflet that went with it, and those in the room were to guess the programme to which the theme tune belonged. Although saying they recognised some music, and there was some foot tapping, guessing was left to G, H [VOLs] and me. D and Br [PTs] said they recognised some, but that was all. The tape finished. H asked each patient if they wanted it, but there was no definite response. Br, holding her head, said that she didn't want to upset the others. H turned the tape over, and lowered the volume. She was then called out of the room

> and she gave the leaflet to me. W [PT], to my right, didn't think it was on (the sound was low and she has some deafness), I doubt P [PT] could hear it (she too is deaf and further away from the set), Br had a headache, and D had her eyes closed and her head to one side, away from the recorder. I read the leaflet. The tape is part of a reminiscence package, designed to bring back memories. [ ]

The physical and psychological care given in day care are elements of 'work' pertaining to the 'care home' environment. The comfort achieved from the satisfaction of basic needs, however, is only one consequence of the activities of the staff. The 'care home' activities of the staff are also considered to give pleasure, or 'pamper' the patients.

### 6.3.3. Pampering

> Extract 24:Field notes BCG7-81 lines 82-91
>
> [ ] The term "manipulative" was used to describe E [PT] and SI [PTs relative] said that E will do whatever she can get away with doing. At home she is encouraged to do a lot more for herself and SI described what sort of things. Perhaps to counter the indirect or implied criticism, A [DCL] then said really the "raison d'etre" of day care is to be pampered. [ ]

This field note extract is an account of part of a conversation between a day care leader and a patient's daughter. The leader puts forward the notion that the main purpose or "raison d'etre" of day care is to pamper the patients. Although this view may be cited in order to justify the actions of the day care staff (who, it is implied, allow the patient to be lazy), the day care leader is contributing towards the construction of day care as a 'care home'.

As a 'care home', day care is a place for pampering patients. Jacuzzi baths, relaxation, beauty treatments, massage and aromatherapy are viewed as pleasurable activities carried out in day care. The type and availability of food also features as a 'luxury' item. These facilities and resources, together with the actions of the staff, serve to pamper the patients. In the following extracts, patients describe how they made to feel pampered when in day care:

Extract 25: Patient interview JM-4-4 lines 1267-1274

Jm: they cater for your every wish: your meal; if you're bad there's a doctor there; and they don't care whether you fall asleep in the afternoon or not, they'll wake you up for a cup of tea and a glass of wine. Oh! You're treated like a visitor more or less [ ]

Extract 26: Field notes BF19-7 lines 326-330

[ ] M [PT] then came out in a wheelchair and joined Ny, My and Ek [PTs] at the table. She was smiling a lot. She talked a lot about Tuesday's day trip saying she "felt like a queen". [ ]

Extract 27: Patient interview MA-8-10 lines 100-117

MA: I thought the really nice thing was the ladies [VOLs] opened their homes and their gardens. That was super. They made such a fuss of us and all the day care people are so wonderful, and- oh it's just good fun really. And food's lovely. I just really like the food, but they have a chef makes you something new for us sort of. There's a lovely table and we sit up there and everybody waits on us and makes us feel very important and, you know, look after us very well, and the food is excellent. So I mean, I know it sounds like something minor, but it's so enjoyable that we have this lovely meal, you know, very reasonable [ ]

The patients consider that the nurses and volunteers pay them a great deal of attention, taking account of what they *want*, as well as need. Consequently, patients are made to feel very special: "very important", "like a queen", or "a visitor". The phrase "anything you want" is used repeatedly by staff in all three sites and is suggestive of pleasure, luxury, comfort; having and doing what ever is desired. This reflects the 'caring' or 'pampering' philosophy of the 'care home'.

Within the 'care home' environment patients are *given* whatever they want. For example staff *give* patients time, outings and meals:

Extract 28: Care assistant interview E-10-4 lines 299-301 and 2829-2832

E: [ ] we give them outings and lunches and things [ ] [the] Nicest thing of all is the fact that you are doing something worthwhile and properly, can give time to patients [ ]

In line with the notion of 'giving' the volunteers bring in cakes for patients to have with their drinks, and wait on the patients at lunchtime.

The 'care home' is therefore a place in which patients are cared for, both physically and psychologically: they are bathed, fed, and listened to. As well as attending to basic needs, the work of the care home extends to consider the patients' wants or desires. Patients are pampered and made to feel special. To facilitate this, staff give to the patients, or as one care assistant stated, they "give of themselves". Food is one item that is commonly 'given'. The volunteers give or serve patients at morning coffee, the mid-day meal and afternoon tea, and food is even cooked by volunteers for the patients. In two out of the three day care sites volunteers bake cakes specifically for patients. In Site B volunteers bring in their offerings on an occasional and spontaneous basis, whilst at site C, a rota system organises who is responsible for cooking the cakes for afternoon tea. These items of food are treated as gifts by patients who pass compliments and say many a 'thank you'.

## 6.4. THE SOCIAL RELATIONS OF THE 'CARE HOME'

When the day care staff *give* the 'care' pertaining to the 'care home' they attend to the patients' physical and psychological needs and wants. 'Care home' patients *receive* the care that is given passively, all-be-it gratefully.

### 6.4.1. The passive receiver

Patients, as 'passive receivers' in the 'care home', do not participate in 'non-caring' activities. The following field note extract briefly describes an occasion in site B when a volunteer attempted to lead a sing-a-long:

> Extract 29: Field notes SF19-1 lines 71-75
> [ ] L [DCL] then went away again. The singer was asking patients if they knew of any songs she could sing. No one answered her. [ ]

In this instance the patients do not participate in the activity, failing to respond even to the volunteer's direct questions. By leaving the room the day care leader did not encourage the patients to participate. 'Care home' patients are quiet, and as illustrated above, often do not respond to requests. This passivity was apparent when on her first visit to the unit the researcher asked the patients for some directions:

> Extract 30: Field notes SF19-1 lines 300-304
>
> [ ] I asked the women [PTs] at the table where the toilets were. They looked at me blankly. The volunteer immediately stepped in and told me where to go. [ ]

In line with this inactivity, and contrary to the expectation that the day care staff is to provide for the patients' needs and desires, patients are reluctant to ask for what they want, and at times may even appear 'resigned'.

> Extract 31: Field notes ST30-1 lines 79-87
>
> [ ] Br [PT] asked me how I was. I returned the question. She had a headache. I said that they could get her something for it if she wants. She then repeatedly said, "I don't want to be a bother", and "We've just got to put up with these things" in a pained tone.

As passive receivers of care, patients allow others to make decisions for them, even when choices relate directly to aspects of their own care

> Extract 32: Field notes SF9-2 lines 209-215
>
> [ ] H [VOL] asked B [PT] if he wanted another sherry: Yes. She poured it for him and then turned to Br [PT] saying "I'm sorry I didn't offer you one, I don't think you can have it but still". Br replied that ' no she couldn't have any with all her tablets' and H went away out of the room carrying the sherry bottles saying that it probably wasn't a good idea on top of all her tablets. [ ]

The patient (Br) is faced with a forced choice. The volunteer makes an implicit offer of an alcoholic drink, whilst explicitly acknowledging that the patient is unable to have one. This patient has diabetes and her food intake is closely regulated by the staff (see section 4.3.2.). The volunteer is to monitor and limit the patient's intake of sugary foods and drink. In this episode, the volunteer is torn between etiquette and her duty to control the patient's sugar intake. Whatever her explanation for not having a drink, the patient is, in effect, agreeing to comply with the decision made by the volunteer. The patient is allowing a decision to be made on her behalf, the patient is handing over the responsibility. On other occasions, choices are made for patients without any acknowledgement that they could play a part in the decision making. For example:

Extract 33: Field notes ST23-1 lines 289-296

[ ] At 12.05 L [DCL] came into the day room to say that lunch was available. Coming over to P [PT] she said, "I'm going to take you into lunch now", and helped P out of her chair and into the dining area. Br [PT] was assisted next and W [PT] made her own way [ ]

As well as accepting the decisions made for them, 'care home' patients also passively accept the care given to them by the staff. At times, the attention can be construed as condescending. For example:

Extract 34: Field notes SF19-1 lines 260-264

[ ] At 13.00 another volunteer came in to the room and greeted the patients, kissing Br [PT] on the forehead as she ate. [ ]

Volunteers and nurses frequently express affection towards female patients in this manner. Familiar names and terms of endearment often accompany these actions.

### 6.4.2. Terms of endearment

Terms of endearment and 'pet' names are regularly used to address patients in the 'care home' environment. For example, in the following extract a care assistant combs a patient's hair after a bath:

Extract 35: Field notes SF19-1 lines 98-103

[ ] E [CA] said, "I'll comb your hair, Darling. I'll use my comb because you don't have one.", and left the room. She came back soon after and combed the woman's hair [ ]

The nurse is particularly 'caring' because she uses her own comb. The personal nature of the task is highly consistent with the nurse's use of the intimate or familiar term, "darling" when talking to the patient. However on other occasions, familiar names are used without 'caring' actions being performed. For example:

Extract 36: Field notes SF2-2 lines 71-77

[ ] H [VOL] arrived with her basket wearing a fox fur around her neck. She went away and soon returned with her tabard on, said hello to B [PT], then to me, and then to Br and Et [PTs] , calling Br a "sweetheart". [ ]

Extract 37: Field notes SF9-2 lines 194-200

[ ] Br [PT] returned with E [CA] at about 12.10 saying that she'd had a lovely bath. E went away and came back with a comb, combed Br's hair saying "That's all I can do with it", and then went away. H [VOL] said that Br looked "bonnie" and "chipper". [ ]

Extract 38: Field notes SF2-2 lines 260-264

[ ] H [VOL] noticed Br [PT] asleep in her chair calling her "precious", and said "conversation is calming. It makes you feel safe and secure.". [ ]

Extract 39: Field notes ST20-2 lines 100-105

[ ] Sn [volunteer co-ordinator] took Br [PT] by the hand and said to me [the researcher], "Isn't she a darling! She's lovely.", and to Br said, "You get thoroughly spoiled here, and at home don't you. That's because we love you." And she left. [ ]

Terms of endearment are used by the staff to show that they love and care for the patients. However, the familiar names themselves and how they are used, express more than affection. Patients are often talked about and talked down to, and the terms applied can be construed as patronising. In the last extract, the term "spoiled" is used to reflect the 'pampering' given to the patient when in day care and at home. This term, however, has negative connotations and is commonly associated with children. The manner in which they are spoken about/to, and the use of pet names, can lead to the infantilisation of patients in the 'care home' environment.

### 6.4.3. Infantilisation

Although family metaphors in day care are used to construct certain female patients as 'mother-figures' (section 6.1.2.), it is members of staff who take the responsibility of 'mothering' in the 'care home'. Like a mother takes responsibility for a child, staff members who construe day care as a 'care home' take responsibility for the patient. In consequence and as previously described, nurses and volunteers make decisions for the patients. Other discursive activities of the 'care home' environment, including the use of terms of endearment, also result in the portrayal of patients as dependent and child-like.

> Extract 40: Field notes ST23-1 lines 36-44
>
> [ ] E [CA] came in and went over to P [PT], greeted her, kissed her cheek saying "how are you darling?". She tapped P on the arm and said "Good girl" as she left her side to go to Br [PT], and said to Br that when she had finished her drink she would put her in the bath she had prepared ("pop you in the bath"). [ ]

The manner in which the nurse addresses the first patient is akin to the way in which an adult may treat a child. The use of the expression "good girl", is particularly patronising. The nurse then speaks to a second patient in a similarly condescending manner: presenting her with a forced choice to do with having a bath, and using 'babyish' language ("pop you in the bath").

The term, "good girl" is commonly used by members of staff to give patients praise and encouragement. For example, in the next field note excerpt a volunteer, the researcher and two patients are doing a crossword puzzle:

> Extract 41: Field notes 20-7 lines 406-415
>
> [ ] Pe [VOL] read out clues and gave answers. N [PT] gave an answer to one and Pe said "Good girl" twice to her. This continued and Ja [PT] and I continued to watch, and at least I half-heartedly tried to think of answers. N started saying she was very tired. I took this to be a polite way of saying she'd had enough but Pe carried on. [ ]

Similarly, staff voice their approval when patients eat the meals that are provided:

> Extract 42: Field notes ST20-2 lines 166-171
>
> [ ] During the meal the three of them watched the TV. This was punctuated by volunteers and E [CA] coming in to check they were eating and congratulating Br [PT] for "doing so well", eating all her food. [ ]

As well as watching over the patients' food intake, the nurses are careful to ensure that there is someone to watch over the patients at all times. On many occasions they called upon the researcher to "keep an eye" on the patients and before the day care leader took holidays, she made plans to ensure the patients were not left alone.

Extract 43: Field notes SF8-3 lines 170-176

[ ] She [DCL] said that she had organised the volunteers to come in on the busy days to help E [CA] because "it's not fair to leave them on their own. They can be an extra pair on hands and stay with the patients when E gets called away". [ ]

In the 'care home' environment, patients are considered to be child-like and dependent, as well as the 'passive receivers' of care. The manner in which staff talk down to patients, using familiar names and baby language and the forced choices and praise given, as well as the considered need for the staff to "keep an eye" on the patients, serves to infantilise day care patients. Problems occur when patients are unwilling to be portrayed and treated in this manner.

## 6.4.4. Conformity and control

Like 'difficult' children, 'difficult' patients are those seen as difficult to control. This idea is summed up in the following extract where a care assistant is talking about a day care patient who spends his time in the main hospice sitting room away from the day care area. He rarely joins in with day care activities.

Extract 44: Care assistant interview E-10-4 lines 2126-2129

E: [ ] he is, I think, very difficult actually to again- to sort of really have any sort of control over. [ ]

This same idea is reflected in the talk of a day care leader who speaks about a patient who complains about the care she receives at home. The nurse asserts that unlike at home, when the patient comes to day care, "she tends to conform":

Extract 45: Day care leader interview L-11-4 lines 1085-1093

L: [ ] She's becoming quite a problem at home, very angry and not conforming at all an' telling them all off and saying that she's going to tell the other side of the family that she's being abused and not well cared for and she's beautifully well cared for at home. [ ]

Difficulties arise in day care, however, when patients do not conform. Some patients are not grateful for the vigilant care and support offered to them as can be seen in the following extracts:

Extract 46: Field notes SF2-2 lines 135-150

[ ] L [DCL] came in to the room and leaning on Br's [PT] chair and told B [PT] his bath was ready. L wore a plastic apron folded up and tucked in around her waist. She carried towels and other linen. B got up from his chair and L said "Don't forget your stick, B" (which was hanging on the back of his chair), and he replied abruptly, "Give me a chance!" in what seemed an irritated voice. L looked at me [the researcher] and pulled a face while she said "Sorry B". H [VOL] said something at this point to B trying to explain L's motives. L and B went away out of the room. [ ]

Extract 47: Field notes SF8-3 lines 218-229

[ ] At one point Bi [PT] went out to the toilet on his own without his stick, Br [PT] reminds him about his stick and he said he was only going across the way. On his way back 10 minutes later, E [CA] was now in the room. Bi wobbled a bit as he came in the room. E said "You didn't take your stick, Bi." To which he replied, "No! I didn't want to.". E then ended this exchange with: "Oh, oh, yes okay." [ ]

The care shown by the staff can be overbearing for some patients. In the following extract the researcher meets another patient who does not gratefully receive the care that is given.

Extract 48: Field notes SW24-1 lines 2-25

[ ] No one was in the day care room. I walked through the sitting/dining room, past a rotund woman sitting in one of the comfy chairs, towards the lunch trolley in the ward corridor. E [CA] was there with three volunteers. E said that I could go in and help 'A' [PT] up to the table in the sitting room because she was about to start serving lunches. I went into the sitting room and sat next to A. I asked her if she was A, and introduced myself. I said I am a student researcher coming over the next few months to study day care. I said that E had asked me to come in and help her to the table. A laughed (in a scoffing way) and said, "I can walk there on my own. I don't need help". She said something to the effect of them always thinking she needed more help than she does. I apologised and laughed lightly with her. [ ]

As well as not being grateful for the care given, some patients do not appreciate being watched over by the staff:

> Extract 49: Field notes SW24-1 lines 137-172
>
> [ ] E [CA] said that she must be going to do the menus, and asked if I would be in the room for a while (to "keep an eye on A [PT]"). A groaned and muttered under her breath something about them all panicking over her, [and later] E again asked if I will be all right with A (who groaned and muttered again), and left. [ ]

As can be seen, patients clearly do not always want the attention that is offered or given to them in day care. These patients are not conforming to the view that 'care home' patients are passive recipients, dependent on the care the nurses and volunteers provide. However, this view is a construction of the discursive activities of both the staff members *and* the patients; the patients also play a part in maintaining the notion that they should gratefully accept the care that is given to them. As well as using this doctrine to guide their own actions, patients who conform to the ideals of the 'care home patient', encourage 'difficult' patients to be gratefully passive. The following extract describes an event whereby a patient refuses a bath.

> Extract 50: Field notes SF22-3 lines 104-177
>
> [ ] Either L [DCL] or E [CA] started talking about Bl [PT] having a bath. E asked him if he'd like one, to which he answered an adamant "NO!". This seemed to go ignored and he looked round the room with eyes wide. (He has cerebral metastases and has difficulty speaking although he has full comprehension) E carried on talking saying that it was a lovely bath, a jacuzzi. Bl mumbled something, I think saying that there was no need for a bath. E asked him if he'd had a bath and he said something about women coming in to help him (he has home carers three times a day). E [CA], Et, V and Br [PTs] all commented about how 'nice' the jacuzzi is, in a sort of persuasive manner. E asked Bl if he remembered the bath from his in-patient stay last week. He said yes. V, Et and Br cooed about the jacuzzi and V said that he could have one everyday if he wanted while he was staying. Bl said something like "Why live?" to which most of the occupants of the room didn't seem to respond but carried on cooing about the bath. Dk [volunteer driver] said something placating like "It'll work out in the end". Bl shook his head and sighed, looked down, moving his legs, stretching them out in front of him. While this talk went on, E and L talked about which bath they'd use. E suggested one, the larger one, but L said no room to move around which is needed when there's two of them in there. E said she'd go and prepare the bath and left. [ ] L went out of the room. E came in with a plastic apron rolled up around her waist and said to Bl that she

> was just running him a bath. He again said "NO!", and "Don't know why". He rolled his eyes saying it was "daft". E then asked no one in particular where his bag was. Bl said he didn't have one. E retrieved it from behind a chair and walked out. Bl looked at me asking with raised eyebrows "was that mine?". I said I thought so. He then sighed, closed his eyes and I thought he said "Go to sleep", he again stretched out his legs, and pretended to snore. Br, Et and V talked about Bl, saying that he looked much better. L came back looking for E saying that the bath was nearly ready. Dk got up and said he'd go. As he went he joked with Bl telling him to "behave" himself. Et called out "Can't do anything else can 'e?!", laughing. Dk laughed too and waved a cheery good bye and said to Bl he'd be back at three to pick him up. E and L then came into the room and wheeled Bl away. [ ]

On this occasion the nurses are intent on bathing the patient, Bl, despite his protestations. Apart from an initial attempt to entice him into the bath, the patient's refusals seem to go unheard by the nurses. The other patients then attempt to persuade Bl to have a bath by talking favourably about the facilities. When this fails, the patients begin to talk about Bl as if he is not there; they ignore him in a similar manner to the nurses. The volunteer attempts to reduce the tension by jokingly telling Bl to "behave" himself, and a patient jokingly acknowledges that Bl has no choice but to comply with the nurses. In effect, the nurses and the patients collude in an attempt to get Bl to have a bath willingly. Although these attempts fail, it is perhaps not surprising that Bl ends up being taken away by the nurses for a bath.

## 6.5. SUMMARY

As a 'care home' day care is about providing a warm, comfortable environment in which staff can give patients special care. The nurses and volunteers are concerned with giving both physical and psychological care and helping patients bath, feed, and talk about their concerns. However, satisfying these basic needs is supplemented by 'pampering', whereby the patients are made to feel special. Unlike the 'outpatient clinic' where staff 'do to' the patients, in the 'care home' the staff 'do for' the patients: the nurses and volunteers give special care. In receipt of this special care, patients are passive, dependent and child-like. Day care staff use familiar names to address patients, make decisions for them, and talk about or down to them. Despite the nurses' disapproval of negative stereotypes of day care, and their attempts to circumvent these understandings, the attentive care given in the ‘care home’ could be said to reinforce the view that day care is for the elderly and/or infirm.

# 7. THE 'REHABILITATION UNIT'

Day care as a rehabilitation unit is concerned with enabling patients to make the most of their lives; it allows patients to be 'normal', to have new experiences, to discover latent abilities, and to learn new skills. As such the 'rehabilitation unit' encourages independence, creativity and achievement. Some organisational aspects of day care promote the construction of day care as a 'rehabilitation unit'. Specific rooms are assigned to facilitate the work of the rehabilitation unit, and time, as well as material resources and staff, are allocated to arts and crafts, occupational therapy and physiotherapy. Although the staff work to facilitate the patients' independence and creativity, much of the 'work' of the 'rehabilitation unit' is carried out by the patients. Patients play an active role, not only in the creative sphere of arts and crafts, but also in the planning of day care activities and decision-making. Patient choice and control is paramount, and it is understood that both patients and staff are necessary in day care. This balance is reflected in the reciprocal nature of the participants' activities.

## 7.1. THE 'THERAPY' OF HOSPICE DAY CARE

Where the 'clinic' is *specialist*, the 'social club' is *fun*, and the 'care home' is *caring*, the 'rehabilitation unit' is considered *therapeutic*. Patients use the term 'therapy' when talking about some of the activities undertaken during the day. Arts and crafts, which could be considered leisure or recreational activities, are routinely labelled as 'therapy' in site C. In addition, the participation of physiotherapists, occupational therapists and complementary therapists necessarily bring the notion of 'therapy' to the fore. 'Therapy' in the day care context, is to do with self-help. Within this framework, day care enables patients to make the best of their lives. It enables patients to discover latent abilities and learn new skills, to be creative and to do things they have not done before. Day care as a 'rehabilitation unit' allows patients to gain some control of their lives, enabling them to adjust to and manage any physical disabilities, as well as enabling them to make choices.

In extract one, a day care leader is talking with the researcher about one of the patients. The text illustrates the 'therapeutic' nature of day care as a 'rehabilitation unit'.

Extract 1: Field notes 20-7 lines 662-690

[ ] T [DCL] then talked about J [PT]. [ ] Although she talks about her health a lot, she

keeps herself occupied organising things and spends quite some time thinking about others. She and P [PT] sent the consultant a birthday card last week. J is finding out birthdays, and organising celebrations for each one, she's been busy advertising the fair next week. She said that the day care is allowing her to live. She said that J had said she really enjoyed the fruit picking and that in all her years, she has never done it before, and she's never been to that area before despite living in [city] all her life, and she had no idea that it was so pretty.[ ]

In this account, the nurse describes how hospice day care is "allowing the patient to live". The 'therapy' of day care is enabling the patient to help herself. As well as gaining new experiences, the patient is able to take control, make decisions and plan day care events. 'Therapy' promotes independence, and as such enables patients to adapt to their illness and associated disabilities so that they can live as 'normal' life as possible. It allows patients to *be* 'normal' by putting aside their illness and disabilities, and enables them to *do* 'normal', everyday things.

Extract 2: Patient interview EK-27-9 lines 765-772

Ek: [ ] But I say we've all got something wrong, but I think you come here to forget that. Sort of be normal I suppose really [ ]

Extract 3: Day care leader interview L-11-4 lines 297-333

L: I'd like to think that they'd say that they just enjoyed coming because they had a good time [said with laughter] or it was so relaxed and it's not what they expected it to be. I think they love the outings, if we go on an outing, and just bringing normality back to their little sheltered world.

AL: So what do you think they're expecting from day care, or want from day care?

L: I think they don't expect a lot when they come. I think they think it's little old ladies weaving baskets, and they're very pleasantly surprised that when they come here that it's not that at all. And talking to them, and listening to them. I don't think they expect too much. They actually like to come and just chat and do sort of normal things you know.

Patients attend a service which is only for those with a terminal illness. Because not just anyone can attend, day care is for a 'special' group of people. It is perhaps a paradox then that the patients come to day care to be, or feel, "normal". The explanation that day care somehow enables patients to concentrate on things other than their illness, is implied in the previous extracts. However, the following extract indicates that having a terminal illness is the norm in day care and consequently it is "normal" to talk about it, unlike in other social settings.

Extract 4: Day care leader interview L-11-4 lines 185-217

L: [ ] to give them a normal life. For the, you know, in a way for them each individual is different, and each individual probably wants something different, but just to try to keep life normal for them, and to be able perhaps talk with other patients so that they're not isolated 'cause if they're at home with just a carer it's difficult sometimes probably to talk about cancer and things and here we're quite open and they can see other patients and I think sometimes if they see patients worse than themselves it actually makes them feel better

AL: Yeah

L: So, you know, we just try to give them a normal, happy life that's left. [ ]

As well as doing 'normal' things, day care is about opportunities to do something not realised previously. For example, patients go to places not visited before as described in extract 1, and try out new activities and therapies. In this view, arts and crafts, complementary therapies, beauty treatments, as well as outings and events, are assumed to allow patients to gain new experiences, uncover latent abilities and learn new skills. For example:

Extract 5: Field notes BT27-8 lines 219-224

[ ] He [a PT] showed me his latest painting saying that he never knew he could do it until he "came here". He said that nearly everyone in day care has one of his paintings which made him feel good. [ ]

Day care as a 'rehabilitation unit' enables patients to find the physical and psychological resources necessary to 'live': to make the most of, and to better, their lives.

Extract 6: Field notes BT30-7 lines 348-353

[ ] MA [PT] said that her friend had commented on how busy she always seemed to be and MA said "it is down to this place" helping her to "make the most of everything

that you can"[ ]

As a 'rehabilitation unit' day care is understood to be 'therapeutic'. It enables patients to help themselves, to feel normal and to have new experiences, as well as to discover their abilities and learn new skills. In short, the 'rehabilitation unit' enables patients to make the best of their lives and to reach their full potential.

## 7.2. THE STRUCTURE OF THE 'REHABILITATION UNIT'

Activities in day care that relate to the 'therapeutic' endeavours of day care include arts and crafts, occupational therapy and physiotherapy. The provision of space, equipment, and staff to these activities, as well as time-tabling, in part serve to construct day care as a 'rehabilitation unit'.

### 7.2.1. Therapy rooms

Sites A and C offer separate rooms for 'therapeutic' activities. Labelled "therapy rooms", these areas house cupboards in which art and craft materials are stored, and a large central table around which chairs are placed. The site C therapy room, which also houses a couch and exercise equipment, is also the place in which patients are seen individually by the physiotherapist. The physiotherapists' couch could be divided from the rest of the room by curtains, and parallel bars stored against one of the walls could be pulled out to allow patients to exercise. In addition, the therapy room in site C is used as an office and base by the occupational therapist. She has a desk in one corner of the room amongst the storage cupboards, by the sink. Most of the surfaces in this room are occupied with paper and other art materials and the walls are covered in patients' artwork.

As well as the exercise and art/craft equipment stored in the therapy room, occupational therapists provide patients with equipment or aids to help them lead more comfortable and/or independent lives. In site C the occupational therapist provided patients with amongst other things, beds, commodes, raised toilet seats, and wheelchairs.

### 7.2.2. Personnel

Specific members of hospice staff are assigned to facilitate art and craft activities. At site A, the Day Care Leader has art qualifications and in site C certain volunteers are routinely allocated to art and craft 'duties'. Different numbers and combinations of reflexologists and aromatherapists visited all three sites. In site C, hospice volunteers specifically trained to give beauty treatments and hand massage visited most days, and one of the physiotherapists was trained to administer aromatherapy massage.

The accessibility and availability of occupational therapists and physiotherapists differs markedly from site to site. Site A had 'in-house' therapists who serve the hospice as a whole, and to whom referrals can be made by the Day Care Leader. Site B has no therapists on-site and individual referrals are made to the nearby hospital when required. Site C, like site A, has ‘in-house’ therapists who, as well as being available to the in-patient unit, are regular and routine participants in day care. The occupational therapist attends the day care staff team briefing, from there becoming involved with individual patients.

### 7.2.3. Daily schedule

The two sites enable patients to become involved in arts and crafts projects. Site A has an 'open' policy whereby patients can do art and craft at any time of the day, and site C has a set two hour period of time each day devoted to such activities. In site C, a half-hour period of time each day is allocated to group physiotherapy, and individual physiotherapy is provided on patient request that same day. Complementary therapies are available by informal arrangement, as no time is specifically set aside for these activities. However, therapists tend to visit in the afternoons, and the beauty therapy, or “hand care ladies” came in according to a “hand care rota” kept in day care.

## 7.3. THE WORK OF THE ‘REHABILITATION UNIT’

As discussed in the previous sections, much of what is ‘done’ in day care as a ‘rehabilitation unit’ is concerned with the notion of ‘therapy’. In this sense, ‘therapy’ works to enhance creativity, to promote a feeling of independence, and to enable patients to celebrate and take joy in their lives. It could be argued that there are two forms of ‘therapy’: professional therapy which is done to a person, and personal therapy which is done by the individual him/her self. The former type of therapy includes aspects of physiotherapy, occupational therapy and complementary therapy, although the ‘therapy’ of day care is not limited to these formalised activities. As a ‘rehabilitation unit’, day care itself is construed as ‘therapeutic’. The ‘work’ of the ‘rehabilitation unit’ reflects the ways in which day care promotes creativity, independence, and joy in life.

### 7.3.1. Creativity

The use of the term "therapy" in site C to denote arts and crafts activities indicates that there is a tacit understanding that these activities are 'therapeutic'. The activities undertaken include painting, drawing, woodwork, model-making, paper crafts, sewing and in-door gardening. To the care assistant in site C, the art and craft opportunities in day care are of major significance:

> Extract 7: Care assistant interview R-15-10 lines 104-113
>
> AL: What's the most important aspect of day care?
>
> R: Art work. They don't come here to do it, but when they do they excel themselves. It's taking that first step. Once they've taken the brush in their hand they enjoy it, look forward to coming back and finishing it off. They can't do that at home.

The nurse hints at the discovery of latent abilities and the sense of achievement experienced by the patients when they begin to paint. In addition, the nurse indicates that day care enables people to do things that would not be possible at home. However, having discovered in day care their ability to paint, several patients purchased their own equipment and continued their artwork at home. Day care, therefore, can be said to facilitate patients' creativity outside the hospice as well as within the confines of the unit. Indeed two patients, inspired by their activities in day care, went to on to attend formal art classes elsewhere.

As well as introducing patients to an activity and enabling them to discover their creative abilities, art and crafts are considered important in the maintenance of self-esteem:

> Extract 8: Field notes BT22-10 lines 180-194
>
> [ ] Mg [OT] sat at the desk and apologised to me for not spending enough time with the day patients doing the activities. She said that she has a lot to do with the inpatients and just hasn't the time any more to spend with the day patients. She seemed aggrieved. She even said "You must think I'm a hopeless OT", adding that she hoped I didn't think she didn't want to do the craft-work. She said it is

important for patients to have a chance to do something of high standard, important to their self-esteem. [ ]

When carrying out art and craft activities patients often become involved in producing items for the hospice. As the following extracts illustrate, objects are made for fund-raising sales, decorations are made to celebrate seasonal events, and certain patients are asked to paint for hospice displays.

Extract 9: Field notes BT24-9 lines 89-97

[ ] Pl [PT] had had his dog painting framed and the volunteers admired it. H [PT], said to me that he was "huffed and puffed", showed me three paintings he had been asked to do for the complementary therapy display going up in the reception area. They were of aromatic plants and were very good indeed [ ]

Extract 10: Field notes BF18-10 lines 100-105

[ ] Ek [PT] was engrossed in sticking pressed flowers onto cards to sell at the Christmas fete. I asked her if they had her on the slave trail and she laughed saying that she enjoyed it.

Extract 11: Patient interview MA-8-10 lines 139-154

MA: [ ] then there's the activities which is fun. I'm not very good at activities but that's very enjoyable. At least they're so much fun and I mean like K [VOL] and all of them you know and D [PT] she's such a card you know. We have a good laugh. And that takes up quite a bit of the morning. But I'm not good at doing these things but it's just good fun and we just laugh the whole time. And we get on with making funny little things or well we've been making Christmas decorations and that's been fun. So you know I enjoy that [ ]

As illustrated in extracts 10 and 11, patients enjoy doing art and craft activities. Extract 11 indicates that even patients who do not feel they have special abilities or skills still enjoy 'doing' something. Patients are able to be creative, learn and develop new skills and gain a sense of achievement, as well as make something for the hospice. However, patients may not always gain enjoyment from their art and craft activities, as is indicated in the following extract.

Extract 12: Field notes 9-8 lines 409-451

> [ ] I asked him [PT] if he felt day care had done anything for him. He looked a little doubtful. He said that he didn't know what it was but he got annoyed sometimes. I asked him what he thought it might be. He said he got fed up with J [PT] and her "attention seeking" and said that he wouldn't do that and that she expects everyone, including himself, to come at a click of the fingers. He said that he wanted to use day care to do things, to try new things, not sit around. He got a bit fed up about that. I asked him about the stools he has been making from kits. He seemed a little unenthusiastic with those. He explained that he had asked T [DCL] if he could "do his own thing" with one of the stools because he didn't like the finish he was getting with the stuff the [hospice] was providing to varnish them. He said that T had liked what he had done, preferring it but then insisted that he use sea grass to make the seat. He didn't want to use it and explained practical and aesthetic reasons why, but said that he had to. It took a lot of the pleasure and satisfaction out of it because it wasn't as he would have done it and he couldn't be proud of what he'd done. [ ]

Whilst talking with the researcher, the patient accounts for his displeasure with day care. Firstly he indicates that he wants to *"do things"*, and secondly he wants to *"do his own thing"*. In the first instance the patient voices a tension between his understanding of the purpose of day care to that construed by other patients. He sees day care as a place to make things, to do something, to be creative. In his view, the other patients see day care as a place to "sit around". Secondly there is tension between the patient and Day Care Leader's understandings of the purpose of "doing things" in day care. The patient is concerned with creating something to gain a sense of personal achievement. He feels his attempts at "doing his own thing" are thwarted by the nurse. It is only possible to speculate why the nurse wished for the patient not to do his own thing. At this point the nurse is preparing for a summer fete and consequently may be more concerned about the 'saleability' of the item the patient is making. This suggests that whilst patients may gain satisfaction and perhaps feel useful by making items for the hospice, for some of them the purpose of art and craft activities is more to do with personal creativity.

In site C, being creative or doing something is often interpreted as patients' 'work'. Despite being enveloped in humour, this understanding is shared between patients and staff. The Day Care Leader frequently referred to the art and craft activities as "work" when calling an end to the preceding group physiotherapy session

Extract 13: Field notes BF6-9 lines 199-202

[ ] A [DCL]commented "Now we can get some real work done!" referring to the activity session.[ ]

Extract 14: Field notes BT1-10 lines 135-139

[ ] A [DCL] then said that with no physiotherapy it meant that there was more time for "WORK!", implying that movement into the therapy room was required. [ ]

Extract 15: Field notes BT27-8 lines 199-202

[ ] A [DCL] asked Ny [PHYSIO] if she could "put them to work now" and there was general movement out of the room to the therapy room. [ ]

Extract 16: Field notes BT30-7 lines 184-188

[ ] Ny [PHYSIO] asked A [DCL] about the time and A said it was time to "get this lot working!" and so there was movement to the therapy room.

Extract 17: Field notes BT6-8 lines 126-132

[ ] At the end of the chair physiotherapy (signalled by a couple of deep breathing exercises, A [DCL] asked Ny [PHYSIO] if the patients are ready for the "honest toil", referring to the activities in the therapy room. [ ]

The patients' art and craft activities may be construed as 'work' because of their role in the production of items for hospice sales, or they may simply be construed as 'work' because patients are perceived to be making or doing something constructive. It is also possible that the shared understanding that patients are to 'work' in day care, may be an adjunct to the ongoing jokes concerning the authority of the day care leader (section 5.3.3.). Humour relating to the authority of the Day Care Leader and the notion of 'work' can be seen in the following field note extract:

Extract 18: Field notes BF26-7 lines 190-219

[ ] There was some talk about A [DCL]- all jokey calling her "Boss" and "Big A", saying that they'd have to find something to do so that it looked like they had been doing something when she comes out of her meeting. Wd [VOL] served squash, and a bit later the aperitif drinks, while ML [VOL] ferried patients to and from the therapy room clutching her piece of paper with names on like it was worth a lot of money. [ ] K [VOL] glued string round a jam jar and then stuck polystyrene balls to it, this was supposed to be what My [PT] was doing. Pl, N, My [PTs] and Wd [VOL] teased him about this masterpiece. When A came out My pointedly picked up her drink as if to look like she was doing something. As she approached, A said, "I hope you've got you're books out for me to look at. I want to make sure you've been working!", and laughed. [ ]

In this instance, the day care leader's authority is humorously acknowledged in her portrayal as a teacher: the patients, or 'pupils', pretend to be 'working' at their books when the 'teacher' returns to the room.

As a 'rehabilitation unit', much of what is done in day care is conducted by the patients. However, whilst patients do art and crafts, the nurses and volunteers facilitate these activities. The following extract of a briefing session in site C, illustrates how the staff are concerned with finding projects that are within the ability range of patients:

Extract 19: Field notes BF4-10, lines 177-188

[ ] There was then some discussion about the activities that Mc [PT] could do during day care. A [DCL] said that he has taken it upon himself to produce a piece of marquetry to sell at the Christmas fete, and his wife thinks he is now not capable. A looked at Pp [VOL] and said that there is a fine line between finding something that people can do which isn't "too demeaning". [ ]

As well as working 'behind the scenes' planning the art and craft activities that can be introduced to patients, the staff join with the patients to view each others' work, give praise and exchange ideas. For example:

Extract 20: Field notes BT1-10 lines 96-109

[ ] Mc [PT] showed A [DCL] and the male patients his marquetry –his first attempt

> (which I thought looked very professional). He was complemented on it and A handed it to Pe [blind PT] describing it to him. Bl [VOL] then joined the men and they all talked about art, Pl [PT] bringing out a picture he's done copying a photo of Bl's two cats asleep. Bl then knelt in front of Mc and Pl and showed them her watercolour paintings (she is a very good artist) and they discussed techniques [ ]

As 'therapy', art and craft activities enable patients to gain a sense of personal creativity and achievement. In trying out these activities they are able to discover abilities they were previously unaware of, as well as learn new skills. Patients can also gain pleasure and satisfaction from doing something and can take pride in their achievements. Art and crafts activities may also generate and enhance patients' feelings of being useful as items are made for the hospice. Members of staff are responsible for *facilitating* arts and crafts and patients are responsible for *doing* the 'work' itself. This division of labour is also evident in the promotion of patients' independence.

### 7.3.2. Independence

Unsurprisingly, the roles of the occupational therapists and physiotherapists are incorporated into the work of the 'rehabilitation unit', primarily by means of facilitating or enhancing patients' independence.

The physiotherapists teach exercises to patients in order to maintain or enhance agility, dexterity and mobility. Although the involvement of physiotherapists differs markedly between the three sites, the role of physiotherapy in enabling patients to maintain their physical independence for as long as possible is accepted. In site C, patients are able to take part in gentle 'chair' exercises with other patients, and they are able to see a physiotherapist individually to learn and practice exercises. Physiotherapists also provide patients with equipment to aid their mobility. Wheelchairs, zimmer frames and walking sticks are supplied to patients to enhance their physical independence. Nurses have a role in facilitating patients' mobility. In sites A and B they are responsible for making physiotherapy referrals, and in all three sites the nurses and volunteers encourage patients who are able to walk between rooms.

Although a laudable achievement in itself, a patient's *physical* independence is considered important in order to promote his/her *psychological* health. For example, the following extract is taken from a morning briefing session in site C. The volunteers, (MH and Wd), the day care leader (A), care assistant (R) and Occupational Therapist (Mg) are discussing the changing circumstances of a patient with motor neurone disease:

Extract 21: Conversation BC20-9 lines 89-148

A: [patient] she had a real slap in the face, was it last Friday? It was wasn't it?

R: That's right, yeah.

A: That dial-a-ride won't take her about any more. I'm not tying to blame them.

Wd: Why on earth not?

A: She's got a modified wheelchair, they can't harness it in.

Wd: Oh!

A: And they seem to have been prepared in the past to put her in two clamps, but it needs four clamps?

R: Yeah, I should imagine four clamps.

A: And they're no longer prepared to take her around.

[simultaneous talk from around the table]

Wd: Hasn't she got a sort of, a sort of ordinary wheelchair to get out and about?

A: No but she wouldn't. She's got one but she won't 'cause her electric wheelchair gives her independence. I suggested that

Wd: They still take Pe [another patient].

A: Yeah but his wheelchair wasn't modified. This is a modified electric wheelchair.

Mg: The place that runs the repairs I would have thought they could have done some additional modification to enable that I mean that's what they do with people's cars now isn't it?

A: Could you, could I leave that in your hands?

Mg: Yeah. I think we'll contact [firm that do repairs]

A: It's a blow to her independence, but even if I say to her 'look I'll give you a car, and I'll give you a volunteer and you go down and do what you want', that's not what she wants.

Wd: She wants to be able to go on her own.

Mg: For as long as she wants

MH: You can understand that, yeah.

Mg: And, I understand the litigation problems.

MH: I mean you can understand dial-a-ride.

Mg: It's all right but, if you can get people with one arm being able to drive, you'd have thought you could done something with a wheelchair couldn't you, but yet it can't.

A: Yeah, right, well that's in Mg's ball court. [ ]

In this instance the staff indicate their understanding of the need for the patient to *feel* independent. It is not so much the practical problems created by the patient's transport difficulties that are at issue. Rather it is patient's psychological welfare that the members of staff are concerned about. It can be seen that the role of the occupational therapist in these matters is significant. In the next extract a patient describes how the in-house occupational therapist at site C provided her with physical aids to allow her and other patients to make the best of life.

> Extract 22: Patient interview MA-8-10 lines 326-354
>
> [ ] Yeah Mg [OT] is very good, but she's I will mention that she's very good like she got me this sort of a bath you know, special chair that goes in. You go up and down. And she's got me a bed that, you know, is surplus to their requirements and she's lent me that. And she's like- she's built up the bed on blocks and all those sort of things that come in very handy. And perhaps if I hadn't have been coming to the hospice I wouldn't have known about them. You know because I was here and I was mentioning to Mg she said, 'Oh, I'll look out the back'. So I find that very helpful. They'll help you if you need things, you know, where they can advise you about who you can see about anything if you, you know- like when they told D [PT] about the hotel. I suppose she probably wouldn't have heard about that if she hadn't been coming to day care, or going off with somebody else. But- those sorts of things, they keep you in touch with what is going on. [ ]

The Occupational Therapist provides patients with materials and tools to enable them to better cope with their physical discomforts and disabilities, as well as advises them about events, places and organisations outside the hospice that may be beneficial. The patient in the extract above describes how another patient was told about a holiday scheme run by a cancer charity, which provides hotel accommodation with medical and nursing support. Although this information does little to enhance a patient's physical independence, it lets the patient know that he/she can do 'normal' things like go on holiday on her own despite his/her terminal illness. It allows the patient a *sense* of freedom or independence.

### 7.3.3. The celebration of life

As a 'rehabilitation unit', day care encourages patients to make the most of life. Although this involves enabling patients to be creative and independent as described above, patients are also encouraged to take joy in their past and present life. To this end, day care participants plan special occasions to celebrate life events. Aside from birthdays, which are celebrated with cakes and songs, specific occasions in sites B and C focused upon major life events.

In site B, a patient's new wedding ring was blessed. The patient had to have her original wedding ring cut off owing to the weight gain she experienced because of her drug treatment. The chaplain offered to bless the new wedding ring if so desired. The patient accepted the chaplain's offer. The day care leader (L) mentions the forthcoming event in the weekly "team meeting" held between the hospice health professionals:

Extract 23: Conversation STEAM2-4 lines192-227

L: [ ] the only other nice thing that I [laugh] well it's not a nice well it's nice for her she had to have her rings cut off and because of her weight gain so she was talking to G [chaplain] about it because she was upset because she'd had to have her wedding ring cut off and G said 'oh we can have a blessing of the rings' so that's what she's going to do on May the third [words of assent from rest of team] and E [CA] and I are bridesmaids!

[laughter from all]

L: and we're going to have a party in the afternoon after.

CW: Is her husband going to come to this?

L: Of course he's coming!

[laughter from all]

L: Can't do it without a husband! Unless we find her another man in between!

SW: I was just thinking!

[laughter all round]

L: So we all got excited about it last week and she was going home to tell her husband and you know I mean that's given her something to look forward to I hope and we go from there. [ ]

The forthcoming blessing of the rings is considered for the patient to be "something to look forward to". By asking the nurses to be bridesmaids, the patient demonstrates that the involvement of day care staff is important to her. In site C, a patient and his wife who celebrated their Diamond Wedding anniversary, also wished to involve day care. The following text is taken from the day care newsletter. The patient wrote the article himself.

> Extract 24: Document - BNewsletter
>
> I was very excited when I realised our diamond wedding was drawing near. I wasn't in the best of health, but my Grandson wrote me saying, "Hang in there Grandad!". F [patient's wife] thought it would be nice to have "God's Blessing" so I asked Chaplain J if that was possible and his answer was that he would be proud to do it. I was very happy and so was F. We invited our two daughters and various other members of our family. The service J prepared for us was very moving. Many staff, helpers and patients filled our little chapel and joined in the hymn singing. Afterwards we had a lovely reception, a beautiful cake, some nibbles and nuts and a glass of wine. The flowers everywhere were wonderful. F had a lovely basket of flowers presented to her and I had some very good paints which I still use. Our family wish to say "Thank You" again for the precious time you all gave.

It can be seen that day care not only provides a venue for special celebrations, but also that the staff and fellow patients are considered integral to the occasion. Day care locale and participants provide an intimate context in which patients can look forward to, celebrate and take joy in different aspects of their lives.

## 7.4. THE SOCIAL RELATIONS OF THE 'REHABILITATION UNIT'

Within the discursive environment of the 'rehabilitation unit' patients are considered active participants. In contrast to the 'clinic' and 'care home' environments, patients do much of the 'work'. They are involved in 'therapy,' which is based on the notion of self-help. Patients learn for themselves how to be creative, independent and to take joy in their lives. Day care staff can therefore be seen as 'facilitators', helping patients to help themselves. In the 'rehabilitation unit' patients can gain choice and control.

### 7.4.1. Choice and control

Patients are encouraged to be active in a 'rehabilitation unit' environment. As well as being encouraged to be active in a physical sense (such as by making things and being mobile), patients are encouraged to be active in the decision-making and planning of day care and their own lives. Members of staff who construe day care as a 'rehabilitation unit' work to ensure patients have choice and control. This idea is expressed in the following interview extract where a Day Care Leader is talking about hospice philosophy:

Extract 25: Day care leader interview A-25-10 lines 192-245

A: Everything's explained. There's informed choice, on the in-patient unit. It's different here in day care. We're not able to do that. We don't do a lot of 'care' here, but give them choice as to what they do in a day, and the programme for the future. They have in-put, and their decisions matter.

[and later]

AL: What does day care offer patients?

A: It offers control. That's what I try to give them back. I spend a lot of the time running around like a headless chicken but behind all that I've got a plan: to make them feel they've got control over life, confidence, make more of themselves, more interested. The difference is very noticeable. Make them feel a little more in control than they have done for quite a long time

The Day Care Leader implies that in order for patients to gain a sense of control over their lives they are encouraged to make decisions in day care. Patients have a choice as to what they do while in day care and are able to get involved in planning day care events.

Patients frequently become involved in the planning of day care in site C. The following excerpt is but one example of the organisation of a day care event.

Extract 26: Field notes BF6-9 lines 325-334

[] The whole group [patients, nurses and volunteers] then became involved in arranging a shopping trip to [town] on one Friday. They talked about the mini bus, parking, where to eat, get drinks, wheelchair access, funding. A [DCL] went a way

> for a few minutes returning saying, "Put this date in your diary for the Christmas shopping trip people - the 29th November" [ ]

In this instance both patients and staff had in-put into the organisation of a day care event. Other forms of patient "in-put" involve events and activities planned solely by patients. For example, in site A, a patient took it upon herself to document participants' birth dates and planned birthday celebrations. Also in site A, patients kept a large confectionery jar in which they collected money for the hospice from family, friends and acquaintances. When the jar became full, it was ceremoniously emptied and the money counted. The jar was then re-sealed and another collection began. Having counted the contents of the jar, the patients and staff then decided together what was to be purchased with the money.

As mentioned in extract 25, where day care is construed as a 'rehabilitation unit', patients are offered a choice as to what to do in the day. Sites A and B had relatively few formally scheduled activities in day care. Apart from having a bath, which was to be done in the morning, patients are able to choose how they are going to spend their time. Few patients actually do anything, preferring to sit and talk. Although in site C the daily schedule is formalised into a timetable, patients are able to choose whether or not they are going to participate in the organised activities. As in the other sites, patients in site C sometimes chose not do anything, as the following extracts indicate:

> Extract 27: Field notes BT3-9 lines 208-214
>
> [ ] MA [PT] remained in the sitting room talking to B and then Mr [VOLs] saying that she was tired and "lazy". B said that she 'should do what she wants. That she was here to enjoy herself, so to do what she wanted'.

> Extract 28: Patient interview MA-8-10 lines 405-410
>
> MA: [ ] One day I came in and I just- and Mg [OT] said you don't have to join in if you don't- you just sit here and that's just what I wanted to do I didn't want to join in. I just wanted to sit quietly

In this context, the frequently uttered phrase "anything you want" is employed to emphasise the priority of patient choice. Patients can choose what they want and do not want to do. Patients are free to choose not to get involved in organised activities, as is illustrated in the following extract:

Extract 29: Field notes SF1-3 14-22

[ ] L [DCL] said that last Tuesday with Jo, Br, W, [PTs] Li and H, [VOLs], L had commented on the "banter" and said that she was going to bring in her "Brit quiz" for them to do to "expand their minds'". Jo had said that she didn't think that's what they come here for. They come in for a "chat and a laugh". [ ]

In site C, the preference for one patient to do 'nothing' was an on-going joke. Despite going into the therapy room for every art and craft session and sitting at the table with materials set out in front of her, she rarely *did* anything apart from watch the goings-on and join in the conversation. The staff joked about this and the patient teased the staff about her choice to do nothing. The following extracts provide examples of this behaviour.

Extract 30:Field notes BT lines 22-10

[ ] All the patients except Pe and E joined in one activity or another. D varnished the spice racks she had constructed, G put polyfiller 'snow' on to candle holders, Pl put pressed flowers onto candles, H drew out Christmas decoration stencils, Kn potted seedlings and bulbs, MA cut out cards to make into gift tags, Mc tried some of his marquetry but changed to construct a bird box with K [VOL] a bit later, As drew round card to make some sort of mat out of decorated paper. My had beauty treatment in the quiet room with C. (As had it next, and then D). When My came back she sat and watched others doing things, making a joke about work being enjoyable – to watch! [ ]

Extract 31: Field notes BF26-7 lines 173-179

[ ] My and Ny [PTs] sitting together, laughed at K's [VOL] attempts to get them to do something and remained sitting doing nothing but watching and talking with the others. Ny said she couldn't do much because of her shoulders and My said she was happiest watching K do something 'for her'. [ ]

Extract 32: Field notes BT30-7 lines 204-215

[ ] My, E and P [PTs] watched K [VOL] as he showed how to marble paint paper. The three of them actually did nothing but watch despite K's joking attempts particularly with My to get them doing something. The three of them wore plastic aprons to protect their clothing. K made reference to the three's

> lack of activity saying things like "Oh it's a hive of activity down here!" and carried on marbling the paper. [ ]

Although attempts were made at each activity session to get the patient (My) 'working', these attempts were never serious. Both the patient and the volunteer (K) knew and accepted that the patient would 'do' nothing. As a result, it became an on-going joke.

As well as choosing what they individually do in a day, patients are understood in the 'rehabilitation unit' to have some control over what goes on in day care. To this end patients are encouraged to assert themselves: express opinions, make decisions and plans, in relation to both themselves and day care. The following extract is a field note excerpt describing a day care carers group meeting. It illustrates the growing assertiveness of a day care patient.

> Extract 33: Field notes BCG7-8I lines 285-298
>
> [ ] At one point Dy [volunteer co-ordinator] talked to the group and particularly Vr [PT's relative] about M [PT] coming out of herself now. She gave an example of how this has been seen. She said that M had shouted across the room at A [DCL] the other day and kept calling until she got A's attention. Dy said that she was surprised but it shows how M is settling in. This was said with humour and A picked up the point saying that they know when someone has settled into day care when they start to talk back to her! [ ]

In this context, the patient's assertiveness is considered appropriate and commendable. The extract illustrates how patients are considered to have "settled into" day care when they have become able to assert themselves; patients are able to make demands and speak their minds.

Because there is the expectation that patients should ask for what they want, it is problematic when they do not. In the following field note extract the Day Care Leader humorously demonstrates the assertiveness she expects from the patient.

> Extract 34: Field notes BF2-8 lines 220-231
>
> [ ] A [DCL] asked G [PT] if he had seen the chiropodist and he said no, that he didn't think he needed to be seen. A then got up and went over to him saying that she was going to be "assertive". "You don't have things done because you don't want to be a bother. I am now telling you that you're going to get your haircut and your feet done next time". G replied with a smile and a quiet "thank you". [ ]

In contrast to the situation whereby a patient is not assertive when he/she is expected to be, tensions are also created when patients wish to be assertive but their opinions or wishes are not heard. On one occasion in site B a staff party meant that the day care patients were moved from the day care room to another smaller lounge in the hospice. The patients were not consulted over the matter and one particular patient voiced her displeasure:

> Extract 35: Field notes ST26-3 lines 191-200
>
> [ ] Jo [PT] didn't think it was very good for the day care patients to be moved to this room, that it was unnecessary for the leaving do to take up all that space. The patients all agreed that they didn't like the new room. Jo said that there ought to be an "out patient's" or "day patient's union".[ ]

On another occasion, after a member of the hospice staff implied that the patient should not be in the day care kitchen, the same patient again referred to the need for a patients' union:

> Extract 36: Field notes ST26-3 lines 223-231
>
> [ ] One of the home care sisters came in to see Jo [PT]. Jo stopped eating and turned around and told her all about [SN]. She said that she ought to start a day patients union to make sure that "we do what we want and go where we want". L [DCL] and the home care sister laughed and agreed. [ ]

The concept of a 'union' relates to the notion of 'work' and concerns the rights of employees. In the extract above, talk of a "union" in day care implies that patients have rights that are not being respected. Indeed, the patient explicitly states that patients should be able to 'do what they want, and go where they want'. The patient's assertiveness here is not appreciated.

Where day care is construed as a 'rehabilitation unit', patients' assertiveness is expected and encouraged. This can be seen in the following extract whereby a Day Care Leader is summing up her view of day care at the end of an interview. She indicates the assertiveness of the patients by saying that she is being 'nagged', and goes on to state how she would like patients to be active members of day care. However, she ends by acknowledging that some people may not wish to be handed so much control.

> Extract 37: Day care leader interview A-25-10 lines 534-552
>
> A: I think we run a good day care. I think we've got a good team. I think we

do a really, really good job and I couldn't keep coming back if I didn't think that. On the other hand I'm always hoping- for instance, the creative writing and PI [patient] nags me about it non-stop and I still haven't managed to do anything about it but I'll keep on trying. I just want people to give me as much in-put as possible. I'd like more patient in-put. On the other hand, they may like it where they're given things to do, not have to think too much about it. Try to get a balance.

### 7.4.2. Reciprocity and co-operation

Reciprocity and co-operation are inherent with the discursive environment of the ‘rehabilitation unit’. The joint planning of events in day care requires patients and staff to work together to the same end. Patients, as well as staff are considered active participants in the process, and are required to voice their views and confer and compromise.

Unlike the ‘clinic’ and ‘care home’ environments, patients are able to give, as well as receive in day care. Because they are encouraged to be actively involved in day care, either planning events or choosing what to do in the day, patients are in a position to be able to ‘give of themselves’. They can give time, effort and ideas. Also, in a material sense patients are able to give to day care. They can get involved with fundraising for the hospice, make items to sell during the art and craft sessions, and contribute to promotional displays and newsletters. As the ‘therapy’ provided by day care works, patients are able to do more for themselves and therefore are in a position to give more to the hospice. Both staff and patients working from within a ‘rehabilitation unit’ framework recognise that patients can have an active in-put into day care. In the following extract of an interview, a patient acknowledges the reciprocal nature of day care whilst talking about how she has benefited from the various activities:

Extract 38: Patient interview D-1-10 lines 1738-1783

D: I've benefited from the sermons because before that I didn't- I am a church-goer. I was when I was younger, but I haven't been because I couldn't walk right down to the town to go to the services, so I'd just have the Sunday service on the telly. But it's lovely to have the service. I do like- I get a lot out of it. It's very, very nice, and he's so down to earth this Jn [chaplain] that I really love it. I love those few minutes. I love the relaxation.

> Get a lot out of– out of that. I like all the therapy and all that we have. In fact I get a lot out of all of that kind of thing, Alison, 'cause I think that it does you the world of good. I mean if you give yourself over to it I think it does you the world of good, so I think you get a lot out of it. I think you get a lot more out of it than y- than you put into it, let's put it that way then, much more in my opinion. [ ]

## 7.5. SUMMARY

As a 'rehabilitation unit' day care provides patients with 'therapy'. Based on the ideal of self-help, patients work towards being creative, independent and to celebrate their lives. Day care staff, time and space are devoted to facilitating 'therapy'. Therapy rooms house materials for arts and crafts, as well as exercise equipment. Specific members of staff are allocated to, and sometimes trained for, art and crafts. Physiotherapists and occupational therapists also have a role in day care. Patients are provided with the necessary equipment and learn how to make things and to be independent. Patients are also encouraged to take joy in their lives and celebrate life events. Because patients are encouraged to help themselves, they are considered active participants in day care. They can be involved in the planning of day care events and are able to decide what they would like to do in a day. Relationships between staff and patients are necessarily based on co-operation and reciprocity. Patients are in a position to give to as well as receive from day care.

# 8. DISCUSSION

This final chapter focuses on the research findings; drawing out the implications for theory, practice, and research, and discusses the methodological drawbacks. There are five main sections. Section 8.1 provides a brief resume of the analytic outcomes of the research and the following section relates these to some of the current issues and theory in hospice care. Section 8.3 provides some recommendations for clinical practice, and section 8.4 outlines the limitations of the study. Section 8.5 assesses the possibilities for future research, before a brief conclusion in section 8.6.

## 8.1. AN OVERVIEW OF THE FINDINGS

Hospice day care can be construed in a number of ways. The current research identified four 'discursive environments' in hospice day care. Firstly, day care can be understood as an 'out patient clinic' whereby the various features of the settings emphasise the role of medical surveillance and treatment of the people who attend. Secondly, day care can be viewed as a 'social club' whereby people attend primarily in order to have fun and make friends. Thirdly, day care can be understood as a 'care home' in which those attending receive special care to enhance physical and psychological comfort. The fourth understanding of 'hospice day care' is different again. As a 'rehabilitation unit', the purpose of day care is to enable those attending to take joy in their lives, to become self-fulfilled and be creative.

There are various forms of social relations existing in hospice day care characteristic of the four discursive environments identified. The 'outpatient clinic' is associated with an unequal distribution of power whereby the hospice workers are in a position of authority as 'specialists'. 'Patients', on the other hand, are passive recipients as the object of care. The social relations of the 'social club' are very different. In this discursive environment the formal roles of 'nurse', 'patient' and 'volunteer' are secondary to the role of 'friend'. Such relationships are based on equality and reciprocity. Somewhat similar to the 'outpatient clinic', the 'care home' is associated with power inequalities. The dominant hospice workers give special care to the patients who are viewed as passive, child-like and dependent. In contrast, the relationships between staff and patients in the 'rehabilitation unit' are based on co-operation and reciprocity. Both staff and patients are expected to give of themselves.

The four discursive environments influence, and are influenced by, the material characteristics of the setting, the practices or work undertaken, and the discursive features of the day care setting. This means that the *physical surroundings,* as well as what is *said* and *done*, have a role in the construction of meaning. This is line with the views that both text and context (Prior, 1997) or material and discursive features (Miller, 1994; Yardley, 1997) are to be considered in qualitative research.

## 8.2. THEORETICAL IMPLICATIONS

Although the Wilkes report (1980) advocated an increase in day care provision in hospice/palliative care, there is little agreement as to the *purpose* of day care, and even less research based evidence about the efficacy, cost effectiveness, or patient and carer perceptions of the service. The current research has identified how participants (patients. volunteers and professionals) construe day care, and how they function within the structural constraints of different organisational contexts. The findings raise questions about the purpose of day care, and may have wider implications for hospice or palliative care as a whole. There are different models or understandings of what hospice is all about, each one suggesting a different way to operationalise hospice philosophy.

### 8.2.1. The 'clinical' model of hospice care

Hospice care following a 'clinical' model gives priority to clinical surveillance. The progress of the patient's disease is monitored, his or her physical symptoms are checked, and treatments are given to palliate these signs of disease. This form of care closely parallels the 'medical' model commonly encountered in hospital settings, but the two care forms are not the same. According to the medical model, treatment is primarily given in order to remove or cure disease, whereas treatments given under the guise of the 'clinical' model are expected to alleviate physical symptoms. The 'clinical' model could be said to akin to the practise of 'palliative care'. As described in section 1.1.3, palliative medicine was formally recognised in 1987, and has become an important component of the hospice movement. The concurrent evolution of the hospice movement and palliative medicine means that the term 'palliative care' is now considered synonymous with 'hospice care'. Although the two are assumed to share ideals, aims and philosophy, it could be argued that the *medical* speciality underlying 'palliative care' still centres on the 'body' and physical symptoms.

Foucault (1973) coined the term 'clinical gaze' referring to the way in which patients come to be viewed by medical staff. Within the 'clinical gaze' the person is viewed as a body to be manipulated and modified. From the signs and symptoms exhibited and described, the patient is reduced to a set of elemental categories specified by the pathology of the body (May, 1992). Doctors then refer to pre-existing categories of knowledge about bodies in order to make a diagnosis. It could be argued that the 'clinical gaze' is prevalent in hospice services favouring the use of a 'clinical' model of care, and in consequence status of the 'patient' is lowered to that of the 'body'. Patients are therefore objectified and dehumanised, and an imbalance of power evolves between the doctor and the patient.

The emphasis on the palliation of symptoms has brought some benefits to patients. Palliative medicine has been particularly successful in the relief of pain (Higginson, 1993a). It could be argued that many cancer patients nowadays are able to experience a pain free death. However, the emphasis on pain control in palliative care has perhaps been at the expense of the relief of other symptoms. For example, breathlessness remains relatively poorly controlled (Corner and Dunlop, 1997).

In relation to models of care, the hospice movement evolved specifically to counter the medicalisation of death. It sought to 'humanise' the process of dying and to care for those who were dying on a holistic basis. The 'clinical' model of care, focusing on aspects of the 'body' and the physical manifestation of disease, is supported by the authoritative voice of palliative medicine and appears to fly in the face of the original hospice ethos. It is somewhat paradoxical that the hospice movement is now closely associated with palliative medicine, and in practise they are often indistinguishable. It is possible that despite the concerns raised about an increasing medical emphasis in the modern hospice movement it is possible that a 'medical' or 'clinical' model of care will dominate many hospice services. As has been the case with day care for the elderly (Pahl, 1989), the power of the medical institutions can easily over-ride other care philosophies. The increased resources from the NHS, whilst lessening the financial overheads of many hospices, may also tie the hospice movement to the existing health system which functions predominantly from within a medical framework. As hospices are required to compete for care contracts from the NHS, it is perhaps more likely that they will take up a clinical or medical model of care in order to be successful. If a 'clinical' or medical model of care is to prevail, it is unlikely that the care provided in modern hospices will be 'alternative' in any form as it was originally intended.

## 8.2.2. The 'social' model of hospice care

An alternative framework for care in hospices is that of the 'social' model. Not unlike the social model described in relation to elderly day care (section 1.4.1.), the 'social' model of hospice care is concerned with friendship, family and fun. According to this view, the purpose of hospice care is to provide patients and their carers with 'time out', entertainment and opportunities to meet people. It could be argued that the 'social' model of hospice care helps to prevent the 'social death' of patients. Social death is said to occur when the patient is treated, and expects to be treated, as if he or she is dead *before* physical death has occurred (Sudnow, 1965). The hospice ideal of the 'good death' according to the 'social' model, therefore, could be one in which the dying person is able to maintain or enhance his or her social relationships until he or she dies.

The value of entertainment provided in hospices guided by the 'social' model, perhaps lies in the simple fun and laughter the patients can experience. Encouraging the use of humour and 'laughter therapy' is considered to be beneficial for patients with cancer (Bellert, 1989; Erdman, 1993; Herth, 1990; Hunt, 1993; Pasquali, 1990). Other authors claim that a well developed sense of humour enables people to respond to negative life events with higher levels of positive affect (Kuiper, Martin and Dance, 1992). The 'social' model, therefore, could be said to value and promote 'positive affect' and a 'fighting spirit' in patients. Although commonly assumed to be beneficial, some caution may be required as patients who do not achieve such positive thinking and high spirits may feel a sense of failure, which it is argued, can only add to the sorrow experienced by the dying (Rittenberg, 1995)

Unlike the care approach advocated by the 'clinical' model, the 'social' model of hospice care is likely to have less of a power imbalance between those who provide and those who receive care. The 'social' model would dictate that in an ideal environment, power is in the hands of the patient and his or her family rather than the hospice workers. Given that hospice philosophy promotes the notion of teamwork between patient, family and professional carers, this may be the model of choice for future hospice services. If, however, the 'social' model aiming to provide respite, company and entertainment is considered the way forward, questions are raised about the need for specialised *hospice* services. Would it not be more cost-effective and equally beneficial to patients and families to make use of existing day care services? Day care services run by social service departments may be equally effective in achieving the aims of the 'social' model of care. Day care services for the elderly may be particularly appropriate because many hospice patients are of an older age. Within hospices, however, there is some antipathy towards day care for the elderly, or at least the stereotype of these services. It is perhaps paradoxical that hospice day care, whilst advocating a 'social' model of care, can at the same time denigrate day care services for the elderly run by social service departments. The current research outlined attempts made by hospice staff to counter the negative image of day care, arguing that hospice day care is special, different, or provides something more than can be found in a day centre for the elderly. This implies that a purely 'social' model of hospice care does not completely cater for all the needs of the patients who attend. People who are dying have needs that cannot be satisfied by the respite, friendship and entertainment functions of elderly or hospice day care services organised solely in accordance with a 'social' model of care. The needs of younger patients are important here because not only are they too young to be able to benefit from elderly day care, but also it is possible that they may experience greater social isolation. Younger hospice patients may be cut off from their peers because amongst the younger age groups terminal illness is relatively unknown and perhaps feared. Hospice patients, therefore, may require some form of psychological support to enable them to cope better with their illness, diagnosis and prognosis.

### 8.2.3. The 'care home' model of hospice care

The 'care home' model of hospice care could be described as the 'sister' to the 'clinical' model. The purpose of the 'care home' environment is to enhance the patients' emotional and spiritual wellbeing, and as a result much of the work of the 'care home' involves talk and listening. Although physical care is carried out, these practices are conducted in order to pamper patients, to make them *feel* special, comfortable and cared for.

It may be the case that in 'care home' environments, the 'clinical gaze' first identified by Foucault (1973) has given way to what May (1992) has termed the 'therapeutic gaze'. May (1992) proposed that where the focus of the 'clinical gaze' is the 'body', the focus of the 'therapeutic gaze' is the 'mind'. Nurses are now encouraged to use 'communication skills' to talk and listen, so that even friendly and informal encounters with patients are considered to be 'work' (May, 1992). It seems that patients' bodies are open to the 'clinical gaze' of the doctors, and their minds are open to the view of nurses using the 'therapeutic gaze'. In the 'care home' context, the use of the 'therapeutic gaze' means that the hospice ideal of a good death is one in which a patient is able to psychologically prepare for, and accept, his or her death. However, some patients may never be able to accept that they are dying with or without the 'counselling' provided by the nurses. Indeed, as May (1992) asserts some patients may even prevent the 'therapeutic gaze' falling upon their minds by remaining silent, and simply not talking about their inner selves.

Whereas in the 'clinical' model of care power lies in the practice of medicine (traditionally a 'masculine' pursuit), in the 'care home' environment it is the nurses (predominantly women) who have power. The gendered nature of the environment and nursing power are two issues relevant to a 'care home' model of hospice care.

Much of the work of the 'care home' involves women. The form of care that is undertaken is traditionally viewed as 'women's work' and it is perhaps not insignificant that the majority of hospice workers (both paid and unpaid) are women. The gendered nature of the 'care home' environment may reflect a bias in hospice care generally and raises questions about whether hospices favouring a 'care home' model of care, can cater adequately for the needs of men.

In the three hospices studied, the majority of unpaid workers were women and many of them spent time talking with and listening to the patients. It could be argued that in the hospice context volunteers, as well as nurses, are able to employ the 'therapeutic gaze'. Although the involvement of volunteers relieves the nurses' burden of care, hospices need to question whether their voluntary workers are adequately trained for the work they are carrying out. This is obviously to the benefit of the patient, but also is of benefit to the volunteer.

It is necessary to consider the 'emotional labour' experienced by carers who deal with other peoples' feelings. Research has looked at the 'emotional labour' in the care given by nurses (James, 1986;Smith, 1992) and care of the dying was described by Smith (1992), as the "ultimate emotional labour" (p.96). James (1989) claims that the regulation of other peoples' emotions, or caring, is often not recognised because it is either not classed as 'work', or is considered merely 'women's work'. According to James, nursing auxiliaries are the carers who do much of the work, but are the most devalued. Perhaps voluntary workers, who have been largely excluded from research, should now be considered the most devalued. It could be said that hospices are exploiting their volunteers, making the most of their free labour. Before hospices can answer this charge, they must provide volunteers with support in dealing with other peoples' feelings, as well as training.

The 'care home' model of care is one in which nurses are given power and authority. Many of the work tasks of the 'care home' environment demonstrate an unequal distribution of power between those who provide, and those who receive care. The nurse who 'counsels' using the 'therapeutic gaze', as well as the nurse who baths or feeds a patient is in a position of great power. Grainger (1993) highlighted the power of the nurse conducting basic care tasks in a study of the talk between long stay elderly patients and nurses during the performance of care routines. Grainger suggested that the discursive activities of the participants lead to the objectification of patients, who were often construed as passive and dependent. Although analysis was focussed on the discursive activities of the participants, the physical context of the recordings is also salient: the nature of the care routines means that patients were often naked or partly clothed, and there was intimate physical contact at times. This only adds to the power of the nurse in the carework situation.

In the study, Grainger (1993) identified the 'nurturing discourse' alongside three other modes of discourse. The 'nurturing discourse' is described as a personal or relational element to interaction, which is constructed through loving, intimate-style discourse. This form of talk is said to help define the routine task situation as caring, loving and personalised, and is realised by loving intonation, endearments, praise, pet names, simplified vocabulary, as well as reassuring and comforting utterances. Within this mode of discourse the nurse, as a 'mother', is in a position of power and the patient is ascribed to a needy, dependent role. There are obvious and important parallels between the 'nurturing discourse' described by Grainger (1993) and elements of the 'care home' environment identified in the current research. Although those who attend day care spend a fraction of their time receiving 'care' compared to those in long stay elderly care wards, the suggestion made by Grainger that patients may experience a loss of personal identity and self-esteem, as well as a loss of control over their environment, may still be pertinent in hospice day care.

### 8.2.4. The 'rehabilitation' model of hospice care

The final model of care, that of 'rehabilitation' follows the dictums of Elizabeth Kubler-Ross who in writing her book, 'On Death and Dying' promoted the notion of 'living until the end' (Kubler-Ross, 1973). The book, often interpreted as representing a stage theory of dying, forwarded the point that the 'dying', are still living human beings who can gain satisfaction out of life and even fulfil ambitions and goals. This aspect of Kubler-Ross' work has been highly influential and has been incorporated into hospice philosophy. The hospice ideal of the 'good death', according to the 'rehabilitation' model of care is one in which the dying person is able to gain a sense of achievement and personal worth.

Although challenged by Fox (1998), results of research conducted by Spiegel (1993) suggest that this ideal can be achieved. In a controlled study, women with advanced cancer were given 'supportive and expressive group therapy' based on seven themes. One of these was, 'developing a life project' whereby patients were encouraged to get on with important plans and goals. The therapy group became a place where life values were examined and new tasks were carefully chosen. As a whole, the intervention was found to be beneficial. Compared to the control group, the women were found to have raised mood level and Spiegel concluded that "confrontation with death in the form of a terminal illness can be a period of growth and life enhancement rather than emotional decline" (Spiegel, 1993 p.1202).

The term 'rehabilitation' could create tensions within the hospice context. The term could be taken to mean 'restoration', which for the terminally ill is perhaps a misnomer. It is unlikely that patients will be restored to their former selves having received this form of hospice care, and it is perhaps immoral to raise such expectations. In terminal illness, the restoration of health is clearly not possible, however assistance can be given to minimise disability and dependence, and to enhance the patient's sense of purpose or meaning. This is the sense in which the term 'rehabilitation' is used. 'Therapy', in the context of this thesis, is employed to help the patient help him or herself.

Within the occupational therapy literature, the term 'therapy' embodies the characteristics of purposefulness, challenge, accomplishment and satisfaction that make up every occupation (Kielhofner, Burke and Igi, 1980). According to Kielhofner (1982) human beings have an occupational nature which means that activity is required in order to maintain mental and physical functioning. When illness (or another condition) robs the person of mental and physical activity, deterioration of both faculties results. In consequence 'occupation' can be used as a therapeutic measure. Occupation, therefore, is not simply viewed as a diversion whereby a patient is given something to do in order to distract him or her from her symptoms or concerns. Occupation is considered essential to the overall functioning of the individual.

The usual 'occupation' encouraged in hospice day care is that of art and craft activities. Nevitt and Eissenhaur (1995) take it a step further and promote the idea of day care as a resource centre for the arts. The authors argue that the presence of artists, musicians and/or writers is beneficial not only because of the 'therapy' that they can provide, but also because they approach the concept of care from a different perspective to that of the professional carer. This, they argue, can add to the dimensions of care provided. The therapeutic value of art and craft activities in hospice day care is said to lie in the sense of purpose and achievement, self-esteem and feelings of well-being that are gained (Gibson, 1993; Nevitt and Eissenhaur, 1995).

Participation in art and crafts also enables the use of imagery and symbolism so that deep feelings can be expressed (Mayo, 1996), and facilitates reminiscence, thereby satisfying the "desire to tell one's own story" (Nevitt and Eissenhaur, 1995 p.205). The products of art and craft activity are also considered to be beneficial for patients; they are able to leave a tangible reminder of themselves and, in making an object to sell for hospice fund raising, they are able to "give something back to the community"(Gibson, 1993 p.265)

Caution is needed, with regard to art and crafts, to guard against the notion that 'a busy patient is a happy patient' (Nevitt and Eissenhaur 1995). This view harks back to the idea that art and craft activities are merely diversional. The 'therapy' of hospice day care using the 'rehabilitation' model, lies in the promotion of self-help, creativity, and life satisfaction. Art and craft activities are therefore considered far more than a method of distraction. Similarly, Nevitt and Eissenhaur (1995) caution against the inappropriate use of the term 'therapy'. Over-use of the term, so that it is tagged on to any activity undertaken by the patients, is considered to detract from the work of the therapist and "reinforce the 'patientness' of the person in receipt of care" (p.206).

The purpose of the 'rehabilitation' model of hospice care is to enable patients to help themselves. It is to encourage dying people to be as physically and emotionally independent as possible. One of the aims of hospice care according to the 'rehabilitation' model, is to hand control to the patient who may have already succumbed to the mores of the 'sick role'. The patient in the 'rehabilitation unit' therefore is in a position of power and is able to make decisions about his or her care as well as the running of the hospice unit. It must be understood, however, that as 'facilitators', hospice workers are ultimately in the position of power. Without their assistance it is perhaps unlikely that the patients would be able to achieve the independence, creative fulfilment and life satisfaction that the 'therapy' of day care aims to achieve. It is therefore of paramount importance that hospice workers advocating this model of care be reflexive and flexible in their approach; willing to examine their role in 'therapy' and ensure therapy does not become overly standardised or prescribed. Considering the relatively small numbers of occupational therapists and physiotherapists in hospices generally, 'therapy' is unlikely to take precedence over medical and nursing care. Unless hospice day care becomes a 'resource centre for the arts' (Nevitt and Eissenhaur, 1995), and/or is staffed mainly by occupational therapists and physiotherapists, it is somewhat unlikely that the 'rehabilitation' model of care will come to dominate.

The present research directly raises questions about the purpose of day care, however the study also relates to the possible models of care operating within the hospice movement as a whole. The four discursive environments, it is argued, relate to opposing models of care explicitly and implicitly functioning within the hospice movement. The hospice approach, cannot be said to be a single unified philosophy and method of care, and tensions inevitably exist regarding the most appropriate model of care. Future hospice services may come to advocate the use of one particular model of care. If the sole purpose of care is to provide patients with a day out and carers a day off, it could be argued that other less specialised services would be more cost-effective. Similarly, resourcing constraints such as the limited numbers of specialist therapists and facilities, means that the 'rehabilitation' model of care is not likely to take a commanding position. Given the authority of the medical institutions in Britain and the large numbers of nurses working within hospices (many of which are 'nurse-led'), it is most likely that either the 'clinical', or 'care home' model of care will come to dominate within the hospice approach.

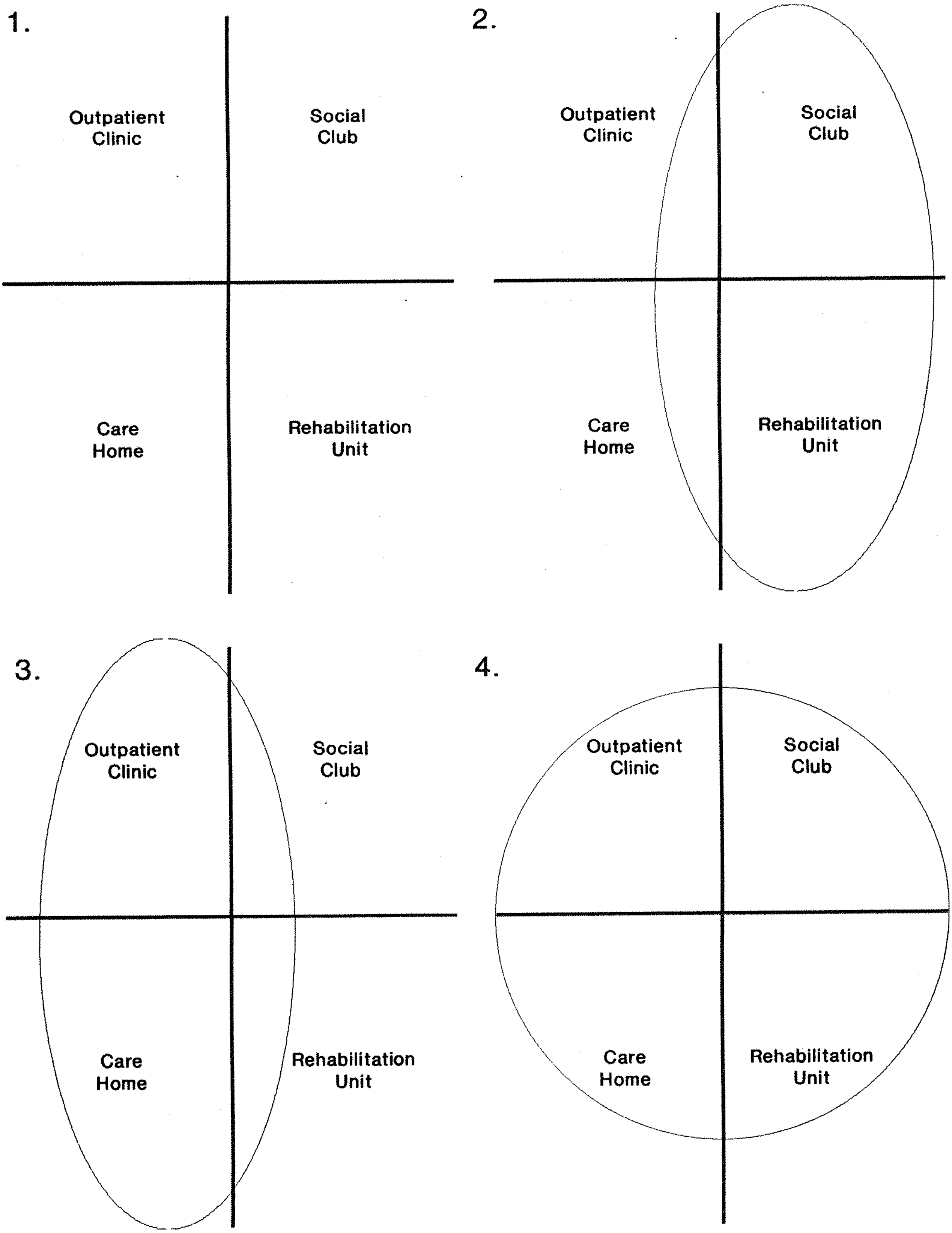
## 8.3. CLINICAL IMPLICATIONS

The research yields a number of implications for those working in hospice day care. Some of the recommendations relate directly to the analytical findings of the research and others are a result of issues highlighted through time spent observing, reviewing documents, and talking with staff, patients and volunteers in the research sites.

### 8.3.1. Planning day care services

A simple diagram of the discursive environments may be a useful tool for staff planning a new, or adapting a pre-existing day care service. The diagram (see figure 1) shows an area divided into quadrants. Each quadrant represents a different discursive environment. Hospice workers (and/or patients) can map onto the diagram how they would like to see their day care. For example, they may view day care predominantly as an opportunity to meet people and to take up some art and craft (figure 2). Equally, day care may be more appropriately seen by others as some where to take a bath and have their wound re-dressed (figure 3). In contrast again, some may view hospice day care as an opportunity to provide or benefit from all four day care environments (figure 4).

Figures 1-4: A Discursive Environment Assessment Tool.



### 8.3.2. Identifying perceptions and expectations of day care

Because it has implications for the form of social relations experienced within hospice day care, it is suggested that hospice workers be aware of their perceptions and expectations of the service, and their behaviour within the day care environment. Equally, it is important to find out patients' understandings of the service they are planning to attend, or are already attending. Again, the diagrammatic representation may be a useful starting point for discussion. This can help to avoid any misunderstandings, staff will be able to dispel any pre-existing negative stereotyping, and patients will be able to assess more effectively if they would benefit from day care.

### 8.3.3. Reflexive practise

Hospice workers need to be reflexive; to look at their own behaviour as well as the structural characteristics of the day care environment, and be aware that even minor features of the day care context can be highly significant in patients understandings and social relations within the service. For example, members of staff need to be aware of the possible effects of wearing a uniform, the terms of address that are used, and even the posters that are displayed in their unit.

### 8.3.4. Day care leaders

It is recommended that a senior member of staff leads a Day care service. If the leader is a nurse, he/she should be of Sister/Charge Nurse grade. The status of the leader reflects the status of day care within the hospice service to which it is attached, and beyond. A nurse of equal grade to that of the nurses managing in-patient units or delivering hospice home care services has some power amidst the hospice hierarchy. Seniority furnishes the day care leader with the authority to make a place for day care, to be involved in the assessment and referral of patients, and to make decisions regarding budgets, planning and diversity of the service, as well as to establish a dominant discursive environment or model of care.

### 8.3.5. Voluntary workers

It is suggested that a number of volunteers be involved in Day care. The role of the hospice volunteer should not be undervalued. Voluntary workers are essential to the smooth running of a diverse number of services offered in a day care unit. Voluntary workers can also help to make the day care environment less clinical by bringing in the 'community'. Recruitment of suitable people is required, and it is proposed that the training of hospice volunteers involves a period of time in day care. Alongside this, there is a need to ensure that volunteers are recognised as part of the hospice team, and are helped to cope with what can be very demanding work. To this end, it is suggested that volunteers are included in day care briefings, and support meetings be provided.

### 8.3.6. Rehabilitation

Overall, the rehabilitative aspect of day care appeared to be the least resourced aspect of day care. If hospice day care is to have a maintenance or rehabilitative purpose, physiotherapists and occupational therapists should be considered key members of the day care team, and facilities and equipment should be easily accessible. Patients may benefit more from services provided by therapists who are based in day care or who visit the unit routinely rather than those who visit day care only after the referral of individual patients. Therapists who attend daily are better able to form relationships with patients and can assess for themselves whether individual therapy is required. Patients in these units are also in a better position to self-refer for therapy. Group physiotherapy is important as it not only encourages patients to exercise, but can assist group cohesion. Similarly, group art and craft sessions can become social occasions. Traditionally the domain of the occupational therapist, art and craft activities are also important for self-esteem and rehabilitation (Stevens, 1996; Thompson, 1990).

### 8.3.7. Religious input

Day care also benefits from the involvement of chaplains. Although the degree of involvement varied from site to site, patients benefited from talking with chaplains both on a superficial and more serious level. The weekly chapel service in one day care site was enjoyed by the older patients particularly. Although the hospice movement claims to be open to people of all religious backgrounds the tacit emphasis on the Christian faith may prohibit the spiritual care of those with alternative beliefs. Consequently hospice services need to consider and cater for patients of non-Christian faith.

### 8.3.8. Carer support

It is recommended that Day care staff consider holding meetings for patients' relatives. Such meetings may enable assessment of the home situation so that emotional and practical support can be offered appropriately as well as provide carers with a break from their relatives. One day care unit studied provided monthly carer meetings. As well as providing a social forum for open discussion of carer issues, the meetings also permitted the day care leader and other members of the hospice team (community volunteer co-ordinator, Macmillan Nurse, and volunteers) to provide further emotional support and practical assistance to both carers and patients. Carers were also able to benefit from reflexology and/or aromatherapy massage in day care. Carer meetings, however, require careful organisation. As well as planning meetings to cater for the needs of the carers (which can vary from week to week), transport and voluntary 'sitters' may be required.

### 8.3.9. Space requirements

The multi-purpose day care requires a number of rooms, specifically allocated for the use of those attending day care. Many of the activities require specific rooms and resources. For example, a relaxation session requires a quiet room with comfortable seating, art and craft sessions require a room with worktops and storage for art equipment, and social gatherings with drinks require a large room with comfortable seating and coffee tables. When planning a day care service, these requirements need be taken into account.

### 8.3.10. Financial provision and the day care ethos

This point concerns hospice funding. Although little can be done to alter the overall financial provision of individual hospice services, day care units funded mainly by the NHS may take on hospital-like qualities. Staff should be aware that the notions of efficiency and cost-effectiveness permeating the NHS can easily infiltrate the day care environment. Patients can be made to feel a bother to the 'busy' nurses, who feel under-valued and under-staffed. An explicit hospice hierarchy, and a sense of 'us and them' referring to the division between clinical and managerial, or senior and 'grass roots' personnel adds to an environment not unlike many modern hospitals. It is possible that hospice services mainly funded through charitable fund-raising afford a less institutional environment, perhaps because they have more flexibility. Fundraising activities in which patients can participate should also be considered. Contributing patients who make items to sell or collect money may benefit from feeling that they are able to give something back to the hospice.

### 8.3.11. Policy and documentation

It has been noted that figures regarding day care admissions, discharges and attendance are lacking, and calls have been made for the collation of such information (Eve et al, 1997; Higginson 1993a; Spencer, 1998). In order for day care to provide the necessary data, accurate records must be kept concerning all people who do and do not attend the service. Day care staff, therefore, should keep detailed notes on patients recording their route from referral to discharge or death. For this reason, day care documentation needs to be separate, but alongside other hospice notes to enable cross communication with other hospice personnel. As has been noted elsewhere, consistent and coherent referral and discharge policies and procedures are put in place (Faulkner *et al*, 1993). Overall, referral and discharge procedures were not clear cut and on occasion resulted in concerns about the 'suitability' of patients. Only one day care unit studied provided written guidelines for referral and discharge.

## 8.4. LIMITATIONS OF THE STUDY

The epistemological assumptions that underlie the current research are different from the doctrines of traditional quantitative research. However, the concepts of 'validity', 'reliability', and 'generalisability', which are often considered the key to 'good' quantitative research are still relevant in the evaluation of qualitative methods, data and findings. According to the positivistic understandings of these terms, the research expounded within this thesis could face a number of criticisms. This section clarifies the epistemological viewpoint of the current research in answer to each of these criticisms. In addition, this section will outline two methodological problems encountered during data collection that may be of interest to researchers planning to use similar research techniques.

### 8.4.1. Difficulty assessing the reliability of method

Traditional understandings of 'reliability' are based on the assumption that methods of data generation can be conceptualised as tools which are standardised, neutral and non-biased (Mason, 1996). However, the form of research articulated in this thesis is not premised on this assumption. This does not mean, however, that there is no need to be concerned with the overall reliability and accuracy of method and research practice. Mason (1996) proposes that to this end qualitative researchers must ensure that their methods and analysis have been appropriate to the research questions, thorough, careful, honest and accurate. To this end, the researcher made every effort to be systematic, rigorous and reflexive throughout the research process, and has attempted to clearly articulate the methods of data generation and analysis in this thesis. It is perhaps for readers to make final judgements as to the appropriateness and accuracy of the research methods employed.

### 8.4.2. Difficulty assessing the reliability of data

Throughout her participant observation in the three sites of study, and particularly during the patient interviews, it was apparent to the researcher that participants tended to talk about day care and the hospice movement in an almost entirely favourable manner. It could be argued that participants, in a mistaken belief that the researcher was evaluating day care, were very keen to present their hospice service in the best possible light. This could be what is commonly known as a 'positive response bias' which would traditionally deem the data 'unreliable'. However, in the current research approach 'bias' is not an issue, or rather, the 'reliability' of the data is not an issue. Firstly, 'bias' in the data is unimportant because the research is not designed to evaluate or measure day care in an objective or standardised way. Secondly, and more importantly, the form of analysis undertaken focuses in on what could be called the 'unreliability' of data; the inherent inconsistencies and contradictions, in an attempt to identify the many and varied understandings of a phenomenon. It may be more beneficial, in this instance, to construe 'bias' as 'diversity'. Instead of thwarting and banishing diversity, as is the tradition in quantitative research, the discursive approach encourages and embraces inconsistency, contradiction and variation in what people say or do.

It could be argued that the methods of data production employed in the current research means that the data gained are not neutral or 'independent' of the researcher. As a participant observer, the researcher herself was the research instrument; the means through which data were produced and gathered in the form of interview transcripts, documents and field notes. Mason (1996) points out that the qualitative researcher is inevitably implicated in the processes of data generation and interpretation. Reissman (1993) proposed that there are five levels of representation in the research process, each of which has a role in the transformation of data. The researcher is key to this transformation. Firstly the researcher 'attends to experience', or selects what is to be observed. Then he/she 'tells about experience', or forms an account of an event or observation before 'transcribing experience' whereby the researcher represents in text what is on tape. Next, the researcher must 'analyse experience', in so doing he/she cuts and sorts transcripts, editing and reshaping what was originally said or observed into a 'hybrid story'. 'Reading experience' is the final level of representation in which others bring their own meanings to bear on the final product of the research. It is proposed that at each stage of the research process representation of the primary experience is incomplete, partial and selective. Data cannot, therefore, exist in an uninterpreted form and it would be naïve to assume that the qualitative researcher using ethnographic techniques of data collection could distance him/herself from his/her observations. Instead, when considering the independence of data it may be more profitable to regard the view put forward by Mason (1996) that "the social world is 'always' already interpreted, and can only be 'known' by socially located 'knowers' (be they social scientists, or non-social-scientist social actors)"(p.140).

### 8.4.3. Difficulty assessing validity of data generation methods

Assessment of validity involves judgements about whether the researcher is 'measuring', or 'explaining', what he/she claims to be measuring or claiming. According to Fetterman (1989), triangulation techniques form the heart of ethnographic validity. By employing different research methods and asking the same question of a number of participants the author claims that the researcher can test one source of information against another, strip away alternative explanations and 'prove' a hypothesis. However, from a discourse analyst's perspective the notion of triangulation is inappropriate. Discourse analysis is not about 'proving' a hypothesis. Discursive studies attempt to explore the variation in people's understandings of the social world rather than to identify a single over-riding 'truth'. Thus, using triangulation methods to strip away alternative explanations is simply nonsensical. Multiple data generation methods were employed in this study: interviews were conducted, spontaneous conversations were audio-recorded, documents were collected, observations were made, and field notes were written. Rather than considering multiple methods as a means of triangulation, Mason (1996) argues that using a number of different research methods "encourages the researcher to approach the research questions from different angles, and to explore their intellectual puzzles in a rounded and multifaceted way. This enhances validity in the sense that it suggests that social phenomena are a little more than one-dimensional, and that the study has accordingly grasped more than one of those dimensions."(p.149).

### 8.4.4. Difficulty assessing validity of interpretation

According to Mason (1996) validity of interpretation is contingent upon the 'end product' of the research. A research thesis should trace the route by which the researcher came to a particular interpretation, making transparent the logic of the methodological choices and analytical decisions that were made and practices that were performed. Every effort has been made to ensure that the research conducted was methodologically consistent and that the thesis (the 'end product') presents clearly the epistemological basis, data collection techniques and analytic stance of the inquiry. Moreover, every effort has been made to make transparent the interpretive or analytical process. Analysis was conducted prior to, and during, the writing of the thesis. An example of the analysis carried out before the writing: the coding, sorting, chunking and re-coding of the data, is demonstrated in appendix 6 to 7. Analysis conducted during the writing process is evident in the analysis chapters (chapters four to seven). Interpretation of the data is transparent or explicit within these chapters which chart the way the researcher thought about the data and provide explanations of the linkages between themes. Although, it is largely up to the reader to decide upon the credibility and plausibility of the interpretation (Hammersley 1990), throughout the analytic process the researcher repeatedly re-examined the data, reflexively questioning the themes and linkages that were made. In addition, the researcher performed three checks in order to convince herself of the validity of her interpretations. Firstly, in an attempt to 'validate' the codings, a 'naïve observer' was asked to read chunks of text relating to a number of codes. The observer was naïve in that he was not familiar with the topic or method of research and was unaware of the code words and coding system used. The observer was then asked to say why he considered a grouping was made in order to see if there was general agreement with the codes applied by the researcher. The process was then repeated for other codes.

A second 'validity check' was conducted during the discursive analysis of field notes, transcripts and documents. Again chunks of data were given to the 'naïve observer' to interpret. He was asked simply to tell the researcher what the material said to him. This enabled the researcher to check her own understandings, to ensure that she was not 'over-interpreting' or plainly misunderstanding the material.

The third 'validity check' took place after analysis was complete and involved taking the findings back to one of the day care sites involved in the research. Although 'respondent validation' techniques have been criticised for giving 'epistemological privilege' to research participants (Mason, 1996), it was reassuring to find that the participants recognised and were familiar with the discursive environments identified, and that the findings generally made sense to them. In addition, the participants' identified which discursive environments they thought best described their day care. Their views closely matched those of the researcher.

### 8.4.5. Difficulty generalising from the findings

It could be argued that because the research was conducted in a very limited number of selected sites, it is difficult to generalise the findings to other day care units or the hospice movement as a whole. From a positivist perspective, the notion of 'generalisation' is based on the assumption that research involves a statistically representative sample of participants or study sites. In the context of this research, however, this notion of statistical generalisation is inappropriate as study sites were selected on a non-statistical basis (see section 3.1.). In the current research, as with many other forms of qualitative inquiry, it is accepted that the findings are contextually and temporally located. It remains possible, however, to draw out issues that are *transferable* to other areas which, with adequate testing, will hold true (Silverman, 1993).

### 8.4.6. Difficulty assessing researcher effects

Through regular attendance and taking part in the various activities and talking with others, the researcher aimed for her presence to become usual and expected, and therefore not at all prominent. In effect, it was hoped that participants would habituate to the researcher's presence. However, in the final stages of data collection, the researcher's presence became more conspicuous as her pregnancy matured. Although a request had been made for hospice workers not to draw attention to her pregnancy, the researcher's very size and shape drew attention to her presence in day care, and the pregnancy at times became the focus of talk. Although it hindered her ability to fade into the background, the pregnancy may have benefited the research in other ways. It is possible that the pregnancy gave the researcher something in common with the patients as both were experiencing 'bodily' changes and physical symptoms. In addition, the researcher may have been perceived as less 'official' and more 'human' and approachable.

### 8.4.7. Difficulties related to 'informed consent'

The Health Trust Research Ethical Committees for each of the three study sites required that 'informed consent' was obtained from day care patients. As detailed in chapter two, information sheets were given, after which each participant was approached by the researcher and asked if he/she would complete and sign a consent form. In order for approval to be gained from the Ethical Committees, the information sheets and consent forms were based closely on the wording and format of the documents suggested by these committees. Implicit within the wording and format of these documents is the assumption that something special is required from participants: that they are either to *do something* or to *have something done* to them, as is the case for much medical research. For the observational aspect of the current research, participants were not required to do something (other than carry on as usual), nor were they required to have something done to them. The consent form particularly served only to confuse participants about the nature of the research and what was expected of them. Much one-to-one explanation was required to inform participants that their written consent was merely required to permit the presence of the researcher, and that nothing special was expected of or from them. Whilst it is understood that full informed consent must be obtained from research participants, written consent of the format required to be used in the current research can set up erroneous expectations, hindering rather than assisting participants' understanding of the research, and may impede naturally occurring behaviour. It was fortunate that the researcher had planned to spend months in each site, as some time was required for participants to come to the understanding that nothing special was required of them. In future observational research, if written informed consent of this nature is mandatory then it may be advisable to plan the study to take place over a number of months rather than weeks to allow participants to settle into 'being normal'.

### 8.4.8. Difficulties tape recording group conversations

Problems were encountered tape-recording spontaneous talk amongst a number of people. For a number of reasons, as detailed in section 2.2.7, the quality of many of these recordings was very poor. In future research requiring the audio-recording of group conversation, it is necessary to ensure that good quality recording equipment is used. Quality recordings will facilitate the transcription process. Researchers may also need to consider the number of people that are to be recorded simultaneously, and the type of talk that is to be conducted. If the talk is between a limited number of people and/or is of a 'formal' nature, the quality of the recording is likely to be better than if the talk is of a 'social' nature amongst many people. Researchers need also to bear in mind the transcription conventions they wish to employ. More detailed forms of transcription (like those necessary for conversation analysis for example) will require extremely good quality recordings so that, for example, in-breathes, out-breathes and overlaps in speech can be easily identified, and pauses timed.

## 8.5. FUTURE RESEARCH

Research is necessary to explore the relevance, prevalence and dominance of the four understandings of hospice day care that were identified in the current research. A national survey of day care units may provide answers to related questions. A telephone questionnaire survey similar to that conducted by Copp *et al* (1998) may be a suitable methodological approach. Questions could explore the material features (for example, room number and type, equipment and facilities, personnel, use of uniforms) and discursive features (service aims, purpose, philosophy) of each day care unit. This approach may achieve excellent response rates, as did the Copp *et al* study, and require minimal disruption to the day care units themselves. However, the findings may reflect the views only of hospice staff as it would be the day care leaders who respond to the questions. An accompanying written questionnaire may therefore be necessary, aimed at volunteers, patients and carers involved with hospice day care.

Further research should also aim to ascertain just who goes to hospice day care. Although such studies should include the views and perceptions of service users, research should also focus on service non-users. In the three units studied no information or figures were kept about the patients who declined or gave up day care. For what reasons do people decide not to go to hospice day care? What are their expectations or experiences of day care, in a hospice or more generally? Are the needs of these people being met? In addition, research should explore the perceptions of the service 'gatekeepers'; those who refer, assess, select and recruit people to attend hospice day care. In the current research day care was not considered appropriate for some patients. The researcher was informed that people with HIV/AIDS, quiet people, and those who had not accepted their terminal prognosis would not find day care beneficial. It may be the case that some patients are not considered appropriate for day care, rather than the other way round. If this is the case then day could be guilty of the charge that hospice services are selective and exclusive, available only to the privileged few (Field and James, 1993; Seale, 1991b).

There are presently calls for research to evaluate hospice day care (Eve *et al*, 1997; Spencer, 1998). For comprehensive and unbiased evaluations to be made it will be necessary for researchers to assess the degree to which day care achieves a number of aims. The current research proposes that there are four main purposes of day care: 1) medical surveillance; 2) social interaction; 3) psychological support; and 4) rehabilitative therapy. In order to ascertain the genuine value of any day care unit, consideration must be given to at least these four areas of the service. If the multi-dimensional approach advocated by the hospice movement is to prevail, care must be taken in research as well as in practice, not to prioritise one aspect of the service over another.

Research is required to look at the status and role of day care within a hospice unit as a whole. Is it perceived as an adjunct, not necessary but a convenient service to have? Is it perceived as a central service, forming an essential link between 'the community' and the hospice? As well as looking at these structural questions it would be interesting to compare patients perceptions of in-patient care and day care. Day care is often considered to provide an introduction to hospice services as a whole. In the current research day care reduced some patients fears of becoming an in-patient, but some patients separated day care from in-patient care claiming that day care is for fun and doing things whereas in-patient care is for the ill.

As well as looking at the status of day care in the provision of palliative care services as a whole, further research could focus on the relevance of the four discursive environments identified in other hospice settings. Hospice philosophy would predict that the multiple purposes of day care are just as relevant within in-patient units and home care, although the different material circumstances of these services may mean that they may be manifest in other ways.

Research exploring hospice and palliative care services has mainly focused on the views of health professionals, patients and carers. Comparatively little research has included or focused on voluntary workers. Although numbers varied in the current research sites, volunteers were an important asset to day care, providing diversity and contributing towards the smooth running of the service. Research is necessary to look at the many roles of the volunteer in hospices, and more specifically to explore the training and support (practical and emotional) that they may require.

Finally, because much of hospice 'work' involves talking and listening, further research is necessary to explore language use in the hospice context. Discourse analytic studies are necessary to examine how language is used to construct hospice and personal realities. Given that much of the spontaneous talk carried out in hospice day care is of a 'social' nature, research is particularly needed to look at the structure and functions of light-hearted talk concerning 'sensitive' issues: illness, death and dying.

## 8.6. CONCLUSION

The present study aimed to begin research into day care for dying people by exploring participants' understandings of hospice day care. The research has identified how patients, volunteers and professionals construe day care, and how they function within the structural constraints of different organisational contexts. The 'discursive environments' described, therefore, have a number of implications for policy and practice, not least of which concerns the basic assumptions or philosophy of care. The identification of the different 'discursive environments' may demonstrate the operation of a number of opposing models of care within hospice and palliative care as a whole, and as such, adds to the argument that hospice care is now at a crossroads (Hockley, 1997). It seems that the hospice movement has not only to consider whom care is for and how it is to be delivered, but also to address the fundamental issue concerning the purpose of hospice care.

## **APPENDIX 1**: Information Leaflets

**a)** The initial information leaflet given to participants detailing the study as a whole.

### Patient Information Leaflet
# An Investigation of Hospice Day Care

A research project by
Alison Langley-Evans
Postgraduate Researcher
University of Southampton

### Who am I?
I am a researcher from Southampton University doing a study in the day care unit of [name] Hospice.

### What am I interested in?
I am concerned with what it is like to be a palliative day care patient and how everyone fits together in the unit. To do this it is necessary for me to develop an understanding of your experiences and perceptions of day care.

It is hoped that the study will contribute towards improved patient care.

### How will I be finding all this out?
1. I plan to visit day care for four months so that I can find out what goes on during the sessions. During my visits I will join in activities, and talk with patients, volunteers and staff. Sometimes I will just sit in the background and watch what ever is going on.
2. During my stay, I would like to tape record some conversations that occur in day care. This will only happen with everyones' agreement and after further information is provided.
3. I also plan to carry out some individual interviews during the study so that I can find out people's ideas and views. Once again, I will provide more information and be seeking permission from individual people nearer the time.

### So what now?
Before I begin the study, I will ask everyone if I may come to observe the day care unit. Any information I collect during the time I am visiting will be treated as strictly confidential. If you prefer, you do not have to speak with me and this will in no way influence the medical and nursing care that you receive.

### How can you get more information?
I will be pleased to provide any extra information that you require about my study. I can be contacted on the telephone number below, or you may wish to contact me via a member of staff at the hospice.

Alison Langley-Evans
R.G.N., B.Sc.
Tel: (01703) 594593

**NOTES/QUESTIONS**

**b)** Information leaflet given to participants regarding the recording of conversations

## Patient Information Leaflet

# An Investigation of Hospice Day Care

A research project by
Alison Langley-Evans
Postgraduate Researcher
University of Southampton

You will already know that I am a researcher from Southampton University conducting a study in the day care unit of [name] Hospice.

### What am I interested in?

In addition to my observation work in the day care unit, I am now wanting to look more closely at how people in day care talk to one another.

### Why is this important?

Although research has been conducted looking at how health professionals talk with patients, little is known about talk between more than two people. Day care enables patients with similar problems to get together, and so the talk that goes on is likely to be informative and influential.

### What am I planning to do?

I would like to tape record some conversations going on in the day care unit. Conversations need not be about a particular topic and can be as long as participants want. Conversations can be held in the day care unit, or in some other location if preferred, and at a time convenient for the participants.

### What will happen to the tape recordings?

I will listen to the tape and write down what is said in the conversation. If anything is said that may identify individuals, it will be changed or left out. In this way what has been said will be anonymous and confidential. No one but myself will be listening to the tape recordings. After the study all the recordings will be erased from the tape.

### So what now?

I would therefore like to invite you to take part in this aspect of the research. Participation is entirely voluntary and refusal will in no way influence the medical and nursing care that you receive. Participants will be free to withdraw from the study at any time. All information will be treated as strictly confidential.

### How can you get more information?

I will be pleased to provide any extra information that you require about the research. You may wish to talk to me in day care when I am about or otherwise I can be contacted on the telephone number below.

Alison Langley-Evans
R.G.N., B.Sc.
Tel: (01703) 594593
<u>**NOTES/QUESTIONS**</u>

**c)** Information leaflet given to participants regarding interviews

### Patient Information Leaflet

## An Investigation of Hospice Day Care

A research project by
Alison Langley-Evans
Postgraduate Researcher
University of Southampton

You will already know that I am a researcher from Southampton University conducting a study in the day care unit of [name] Hospice.

### What am I interested in?

In addition to the observation work in the day care unit, I am interested in finding out about patients' individual perceptions and experiences concerned with day care and their illness.

### What am I planning to do?

I would like to talk individually to you in a private setting. I will be asking questions relating to your experiences, feelings and perceptions of day care and illness. The interview will be tape recorded and will last as long as you feel you want to talk, but will be no longer than 20-30 minutes.

### What will happen to the tape recordings?

I will listen to the tape and write down what is said in the interview. If anything is said that may identify you it will be changed or left out. In this way what has been said will be anonymous and confidential. No one but myself will be listening to the tape recordings. After the study all recordings will be erased from the tape.

### So what now?

I would therefore like to invite you to take part in this aspect of the research. Participation is entirely voluntary, and in will in no way influence the medical and nursing care that you receive. You will be free to withdraw from the study at any time. All information will be treated as strictly confidential.

### How can you get more information?

I will be pleased to provide any extra information that you require about the research. You may wish to talk to me in day care when I am about or otherwise I can be contacted on the telephone number below.

Alison Langley-Evans
R.G.N., B.Sc.
Tel: (01703) 594593

### NOTES/QUESTIONS

# **APPENDIX 2:** Consent Form

## Consent Form

Study Title: An Investigation of Hospice Day Care

Have you read the patient information leaflet? Yes / No

Have you had the opportunity to ask questions and discuss the study? Yes / No

Have you received satisfactory answers to all your questions? Yes / No

Have you received enough information about the study? Yes / No

Who have you spoken to? ……………………………………………………………

Do you understand that any responses you give will not influence the medical and nursing care you receive?
Yes / No

Do you understand that you are entitled *not* to speak with the researcher at any time, and without giving a reason?
Yes / no

Do you agree to take part in the study? Yes / No

Signed ……………………………………………………… Date ……………………

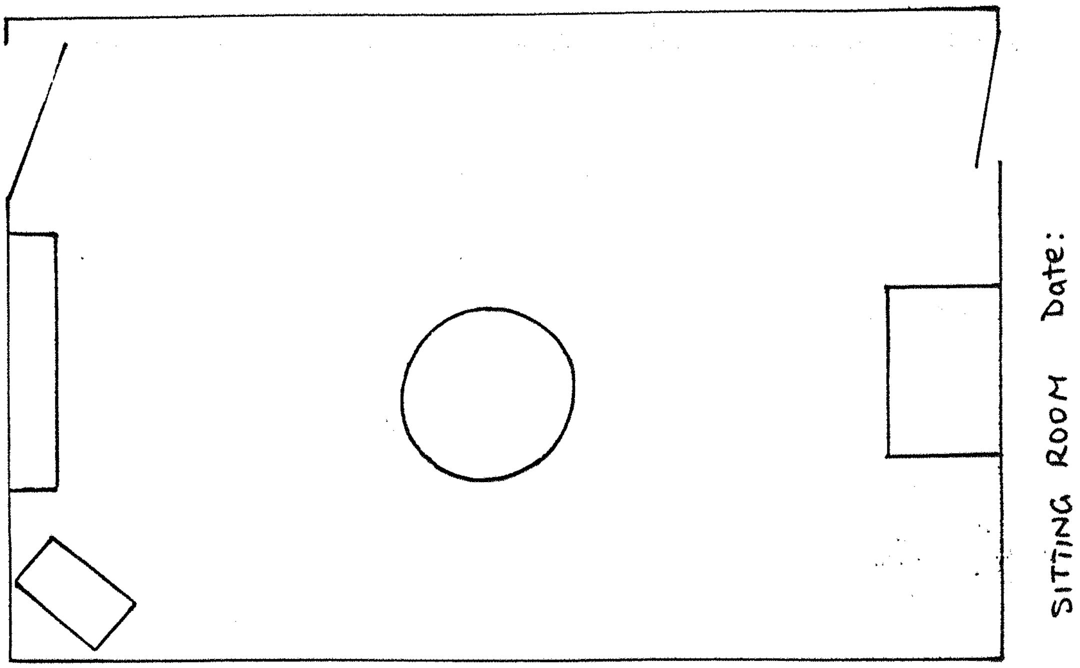
(Name in block letters) ……………………………………………………………

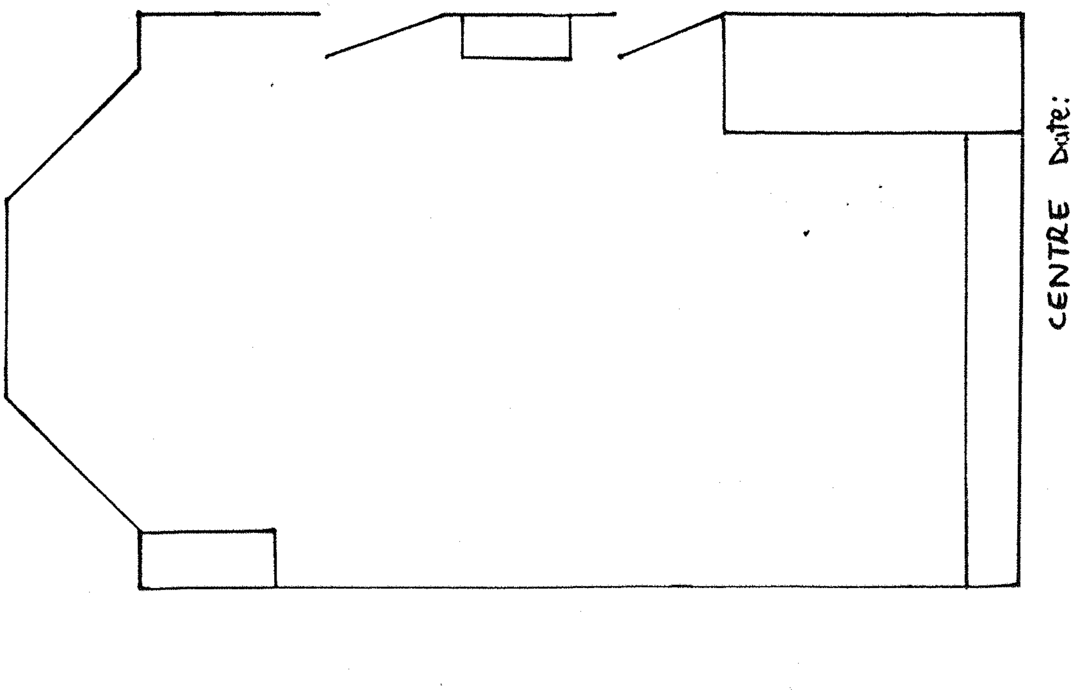
Do you agree to allow the researcher to gain access to your medical notes?
Yes / No

Signed ……………………………………………………… Date ……………………

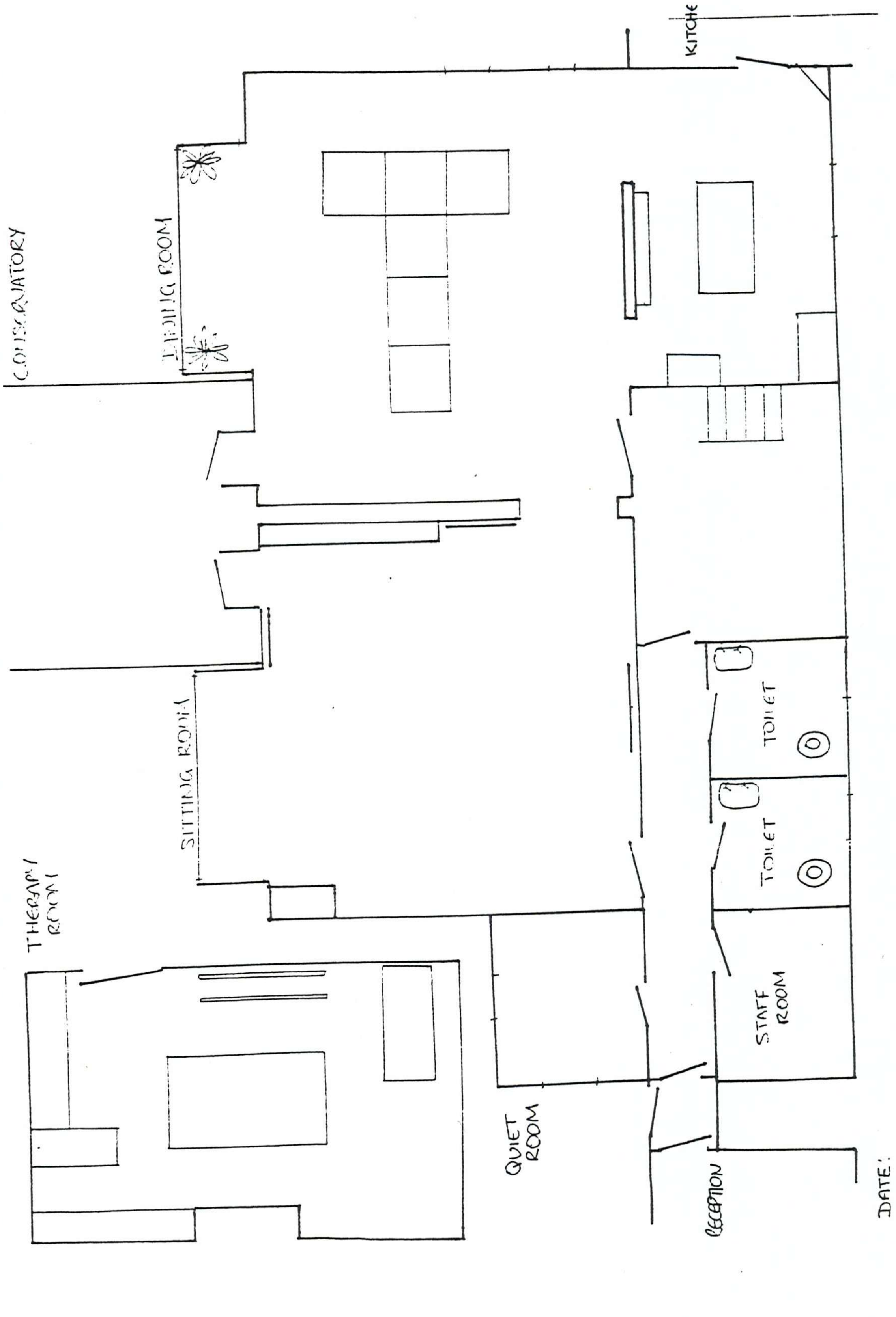
## APPENDIX 3: Room Plans

**a)** Site B





**b)** Site C


KITCHE
CONSERVATORY
DINING ROOM
SITTING ROOM
THERAPY ROOM
TOILET
TOILET
STAFF ROOM
QUIET ROOM
RECEPTION
DATE:

## **APPENDIX 4:** Interview Checklists

### **a)** Patient Interview Checklist

HOSPICE

- first contact with hospice
- feelings about referral
- meaning of 'hospice'
- similarities and differences with other health services

DAY CARE

- reasons for coming
- what it offers
- how far expectations fulfilled
- aspects enjoyed
- aspects not enjoyed
- what tell others
- feelings about meeting and talking with other patients

ILLNESS EXPERIENCE

- how found out/realised ill
- what doctors said
- feelings about diagnosis
- feelings about prognosis
- more/less information wanted
- treatments and their outcome
- expectations of the future
- talking with patient, staff, friends and relatives

**b)** Nurse Interview Checklist.

PERSONAL DETAILS

- age
- marital status
- qualifications
- experience
- why hospice work

HOSPICE

- hospice philosophy
- aims
- what it means

DAY CARE

- aims
- similarities and differences compared to other day care services
- preferred name for service/ unit
- who is eligible
- selection and recruitment
- advantages and disadvantages
- what do patients want/enjoy

PATIENT INSIGHT

- meaning
- hospice policy
- talking with patients re prognosis
- difficult questions
- coping

## **c)** Volunteer Interview Checklist

### PERSONAL DETAILS

- age
- marital status
- occupation

### VOLUNTARY WORK

- first contact with hospice
- length of time in hospice
- reasons
- training
- aspects enjoyed
- aspects disliked
- coping

### DAY CARE

- aims
- preferred name
- what it offers
- advantages and disadvantages for patients

# **APPENDIX 5:** Transcripts

## a) Example of a conversation transcript.

Site B, 21st February 1995: Conversation between the care assistant (E) and a patient (A), who is having a bath. A is fifty-five years old and has a brain tumour. The transcript has been entered into, and numbered by *the Ethnograph*.

```
: E: You don't want us to sing any bawdy       1  -#
:       songs then?                            2   #
: A: No!                                       3   #
: E:    [laughs]                               4   #
: A:    [laughs]                               5   #
: E:    [fiddles with bathing equipment]       6   #
:   Shall we tell some rude jokes              7   #
:   that'll sort her out won't                 8   #
:   it[referring to the researcher].           9   #
: A: Yeah [laughs]                            10   #
: E: D'you know- d'you know any rude          11   #
:   jokes um A?                               12   #
: A: No.                                      13   #
: E: Oh! What a pity!                         14   #
: A: [laughs]                                 15   #
: E: This is going to be a very               16   #
: dull recording again I think [laughs]       17   #
: A: /hm/                                     18   #
:   E: Right then, we've got some wash        19   #
:   an- wash an' go.  Oh! No, you've got      20   #
:   your  own shampoo.                        21   #
: A:     Wash anþ go!                         22   #
: E:    Yes, you've got you're own            23   #
:   shampoo I think haven't you?              24   #
: A: [groans as takes off clothes]            25   #
: E: See what goodies you've got in           26   #
:   here. It's a very useful bag that         27   #
:   isn't it? It's like a flight- an in-      28   #
:   flight bag isn't it?                      29   #
: A: But it's heavy.                          30   #
: E: You got yer johnsons baby [bubble        31   #
:   bath] I         know.  Do you feel as     32   #
:   if you're going away for the weekend      33   #
:   when you bring it?                        34   #
: A: I know I-I-I (12 broken syllables)       35   #
: E: Right. Um. I won't put the- your         36   #
:   own bubble stuff in 'til I've washed      37   #
:   your hair.                                38   #
: A: Okay.                                    39   #
: E: Because yours is very very bubbly        40   #
:   isn't it?                                 41   #
: A: /Mm/                                     42   #
: E: Are you gonna have yer ten minutes       43   #
:   for the jacuzzi to soak again             44   #
: A: Well                                     45   #
: E: as you usually do?                       46   #
: A: Yeah if you got time.                    47   #
: E: Yes, course I have. Yes, that's          48   #
:   okay.     I'll take the recorder- I'll    49   #
:   take the tape recorder out though         50   #
:   while you're-                             51   #
: A: Yeah!                                    52   #
:   E: doing that [helps A take off           53   #
:   shoes]                                    54   #
: A: I've had a a-                            55   #
: E: Yes, your husband said actually          56   #
: you'd been to the chiropodist               57   #
: A: Yes.                                     58   #
: E: That feel better? I bet they feel        59   #
```

: better don't they?
: A: Oh yes!
: E: Yer feet?
: A: Yes.
: E: Yes good. There's nothing like
: having them done professionally is
: there? Y'know I mean.
: A: (there's a)
: E: Were you snowed in at all this
: last few days?
: A: Yes
: E: Were you?
: A: I couldn't er er get out yesterday
: E: So actually it's just as well that
: today was your day for coming þcos
: you couldn't have got in yesterday
: I don't expect could you?
: A: No
: E: Wait a minute. One minute darling.
: Let's have it this way [A is getting
: undressed] That's it. There we are!
: A: Well I wouldn't have come.
: E: No well it wouldn't have been er
: probably very sensible to try
: actually. I was surprised our
: patients did manage to get here
: yesterday.
: A: Yeah.
: E: W [a patient] managed it and she
: lives up the- the top of a very very
: steep hill an' I was a bit worried
: about her driver but he was okay. JR
: brought her in
: A: Yes.
: E: and er it was all right.
: A: I can't do that [possibly
: referring to taking an item of
: clothing off]
: E: But one of our other drivers, RM,
: he actually skidded right round on
: the road on the way to fetch Br!
: A: What've I got to do? l-leave
: this on? [a wound dressing]
: E: Yes leave it on at the moment um
: it'll come off in the water probably
: anyway A. I'll ask um one of the
: staff for another one for you.
: A: [grunts removing clothes]
: E: And that dressing's okay on there
: isn't it?
: A: Yes she put-
: E: So I'm not going to- I'm not going
: to touch that today.
: A: No. It's horrible.
: E: Is it?
: A: Yeah
: E: Your husband said it'd gone a
: little bit bigger. Has it?
: A: Yeah.
: E: Oh, well we'll- we'll- District
: Nurse will be watching it so y'know.
: A: She comes on Tuesday an' Friday.
: E: Oh! she comes twice a week?
: A: Yes.
: E: Good [pumps up hoist]
: A: Don't forget to give me that drop
: of water.
: E: [laughs] Oh! It's a fantastic one
: though A it doesn't look like a wig
: an' it looks so nice on you. Does
: it make you- does it make your head

: itch?
: A: Um. By the end of the day it makes
: it- [noise from hoist drowns speech]
: A: -makes my h- hair hurt.
: E: Does it?
: A: Well whether it's all matted up
: with it.
: E: Mind you, you don't need to leave
: it on all day if you just keep it-
: put it on when you go out. I-
: A: No! I keep it on!
: E: believe it gives you or d'you
: wear it in the house?
: A: Yes, because my son an' my husband
: like it.
: E: Oh, right. Well it does look nice
: on you. I mean, I can
: understand that. [fiddles with
: mechanics of bath þ lowers A into
: the bath] I can understand that
: because it looks really nice.
: A: Oh! this is lovely! (that) water!
: E: There we are. Okay?
: A: /Mm/ Sit-up.
: E: I'll do it gently.
: A: Yeah.
: E: þCos it might feel a little bit
: warm to start with. Y- you, that's
: right, put your legs out in front of
: you. I can bring the bath up, y'see,
: that's the advantage of this one. We
: can bring the bath up to meet the
: chair [switches on mechanical
: hoist](2 syllables) See there you
: are!
: A: Woha!
: E: I know it's brilliant isn't it?
: A: Well I never!
: E: [switches off hoist] There you are.
: How about that?
: A: Super. Er, you can um-
: E: I'll do your hair first, an' then
: Um, then I'll put the jacuzzi on
: before I leave you to have your ten
: minute soak. That'll be nice won't
: it? Do you want to put the flannel-
: [clanking noises] Oh this has got
: wet.
: A: It doesn't matter.
: E: Is that all right?
: A: Yeah.
: E: Just protects y' face.
: A: [mumbles]
: E: Only I'll do it before the water
: gets too bubbly. Has any more come
: out?
: A: Yes, some
: E: Has it? Oh it's not really
: noticeable but-
: A: (lousy) I'm supposed to be having
: it cut.
: E: I was gonna say, you said last
: week you were gonna have it trimmed.
: A: Yes
: E: What happened then?
: A: Well I haven't got round to it.
: E: Oh right.
: A: Um
: E: I can see I shall have to go out to
: nag you about this then.
: A: No. I- I'm gonna take um, yþsee

there's another thing that upset me
about K [a fellow patient who has
died] um, because you cut her hair
and I said last week how nice it was
coming back.
E: Well d'you- I mean, I'm quite happy
to trim yours A. I mean if you like,
but I mean I'm not a professional
hairdresser.
A: No.
E: And I just feel- K's actually, I
mean, she didn't have anything like
as much hair as you've got. An'
really all I did was just trim a
couple of bits at the side and round
the back of her neck, didn't I.
D'you know what I mean? You've got
more hair. Yours could be, sort of,
needs really needs to be trimmed
into
A: Yes my-
E: I think a bit of a style. I mean
it's up to you really. I mean I'd
have to get some decent scissors
y'know.
A: Yeah I-I-I have got a hairdresser.
E: You haven't?
A: I have.
E: You have. Right.
A: Well what-
E: She'd come to the house wouldn't
she?
A: Yeah. Yes. W-what I'm saying is
that's another thing that worries
me. Um, I had all my hair cut off
and then s-s-something happens tþ
me, y'see?
E: What- how- Yes, but I mean what's
hh I don't quite understand though
what you mean A, as far as- What's
the connection between having your
hair cut an'-
A: Well it matters to me, that- Oh, I
can't explain.
E: Well, why don't you ring up your
hairdresser explain to her that you
just want a nice trim.
A: Yes
E: And ask her if she'd come out to
the house. I'm sure she would
wouldn't she?
A: Yes but- Yes, um cos I need all
that back bit which is getting a bit
thick.
E: Yes. It is, yes.
[slopping water sounds]
A: Right.[slopping water sounds] Oo!
E: It's up to you A, I mean y'know you
don't have to have it trimmed at all
but I think you'd probably- It would
look nicer if you did have it just,
y'know, nicely trimmed
A: (sorted)
E: There we are. I'll just go get a
towel an' just dry y' head in it
A: Ohh (that's nice)!
E: Right. I'll let you dry your face
in a moment as well.
A: We mustn't lose any [hair] today
in it! [laughs]
E: Oh no! We went fishing last week

: didn't we!
: A: Yes, we did! (4 syllables)
: E: There we are darling.
: A: Uhh [large sigh]
: E: D'you want to just dry your face?
: Hang on a minute I've let that end
: in the water which wasn't very
: clever anyhow! Alright?
: A: Yep.
: E: Then I'll put your bubbles in and
: put the jacuzzi on.
: A: Er, I-I-I should be careful doesn't
: go over [the side of the bath].
: E: No it wonþt go over. It wonþt go
: over A. We've had th- It's never
: gone over yet, and this is the
: correct- The bath automatically
: stops filling when it's at the
: correct level.
: A: Yeah
: E: So it's not as if the bath is over
: filled or anything A, so. [jacuzzi
: switched on - very loud noise]
: A: Ahh!
: E: There we are. I'll do you back for
: you.
: A: (Super)
: E: Just give you a wash and then, um
: A: Could you tell me: Have I got
: anything like this [referring to leg
: wound]on my back?
: E: You havenþt got anything on your
: back. You havenþt even got any
: moles or freckles on your back. Your
: back is totally clear.
: A: Good. [lahs a tune] The next thing
: Iþve got to do is con-consider
: seriously having my rings cut off.
: E: Is it getting tight on you finger?
: A: Yes.
: E: Oh well then, you will need to. Oh
: yes, itþs making your fingers swell
: isnþt it, yes.
: A: (S'alright then)
: E: You do- you could have that done ar
: a jewellers couldnþt you. Any
: jeweller will do that, I think.
: A: Yeah. So.
: E: Yes, but he can put a piece in.
: Y'know theyþll put a piece in for
: you
: A: Yes, somebody said that.
: E: And enlarge it.
: [long pause]
: E: Right A. I'm gonna leave you now,
: shall I?
: A: Yeah.
: E: Have a nice soak.
: A: Yeah.
: E: And thatþs already on itþs
: countdown [timing device](3
: syllables). I'll take the tape
: recorder away with me. All right.
: Here we are darling, I will leave it
: like that. I'll give you the bell so
: that you can call us if you need to,
: if you need anything.
: A: Well I'm really frightened it w-
: will go over.
: E: I'll judge the time on my watch
: anyway, so don't worry.

: A: Er. W-when you've g-got smaller #
: patients in here, theyþre- that um #
: E: No weþve got a piece that we can #
: put in the end of the bath, #
: actually. #
: A: I see. #
: E: You see, youþre all right arenþt #
: you. Are you touching the end? #
: A: Yeah. #
: E: Yeah, itþs okay. Oops! Now you #
: haven't lost that flannel have #
: you? Oh, well done! #
: #
: [recorder removed from room as E #
: leaves. 10 minutes later E returns #
: without the recorder and I go after #
: her and knock on the door - jacuzzi #
: in operation so lots of noise] #
: #
: E: Come inside Alison. A won't mind. #
: AL: Oh no, it's all right, I won't. #
: E: [comes to door] Come in a minute A #
: doesn't mind. #
: AL: Oh I canþt. That's not fair. #
: A: Why? #
: AL: I feel awful. #
: E: She said why then. #
: AL: I'm interrupting your privacy. #
: [loud noise from mechanical hoist] #
: E: Well, you didn't mind Alison coming #
: in did you? #
: [hoist stops] #
: A: No. When you are a patient y- you #
: f-forget about privacy. #
: E: Oh! Well, no. No, that's what we #
: don't forget though, actually. #
: That's what we donþt forget. #
: AL: I'll go outside. #
: E: No we don't forget that. We don't #
: forget that here, A. Not at all. #
: That's important actually. Right, is #
: it [the tape recorder] on again. #
: [laughs] #
: AL: See you later. #
: [AL leaves the room] #
: E: She's doing this to me. I've just #
: heard my voice on the tape recorder. #
: Oh anþ- anþ I do not like it. #
: A: It never sounds like y-you do. #
: E: I know. I'm just going to rinse #
: you- rinse you off, actually A. #
: A: Yes.[laughs and then lahs a tune] #
: [loud splashing noises] #
: E: (3 syllables) I'll just make it #
: nice and warm for you. Is that all #
: right? #
: A: Yes. [lahs tune] #
: E: I'll bring you up a bit, A. Just a #
: minute, I'll bring you up. Let this #
: down and bring you up. [mechanical #
: hoist on] Right. Okay? #
: A: [lahs tune] Oh! #
: E: Oh, that's lovely. You've been #
: rinsed as well today. (12 syllables) #
: A: [lahs tune] #
: E: Is it lovely? The bath? #
: A: Yeah.[bath pump switched on] #
: What's that noise? [noise stops] #
: Anyway, thank God for that! #
: E: Oh yes, it's just that. Right. #
: A: Ooh! #

: E: There we are. Put this towel round #
: your back a minute, then you won't #
: start to feel chilly. #
: A: Oo! #
: E: I'll let you down now. Going down. #
: Basement. Haberdashery. #
: A: [laughs] #
: E: Kitchenware. Right. Lovely. #
: Well that was nice wasn't it? #
: A: Lovely. Yeah. #
: E: D'you know Br, [a patient] she does #
: love this big bath now. #
: A: Does she? #
: E: I mean she's that tiny little thing #
: in the middle of this great big bath #
: A: I know #
: E: and she's all smiles #
: A: Ow! #
: E: beaming away! #
: A: Ach. Oh my hand! #
: E: What have you done? #
: A: It's b- #
: E: Has it gone um, has it gone into a #
: spasm, has it? #
: A: Yeah #
: E: Oh! #
: A: Only for a minute. #
: E: Yes, yeah. #
: A: Ow! #
: E: D'you get cramp at all very much #
: still in the night or anything? #
: A: Nope. #
: E: You don't? You do? #
: A: No. #
: E: Oh. Well, that's good. #
: A: No, but they bought me over this #
: week a-a bed. L-like a a s-soft #
: mattress. And I don't like that very #
: much. #
: E: Oh, don't you? #
: A: No. #
: E: Oh, right. #
: A: Too- too soft. #
: E: Is it? #
: A: Yeah. #
: E: /Mm/ #
: A: My husband likes it. #
: E: He likes it does he? Oh, right. #
: A: Um h-he s-slightly hangs it over #
: the edge of my bed as well. #
: E: Does he? #
: A: (7 syllables) #
: E: Yours is a full size double though, #
: is it? #
: A: No, it's not actually. It's a- #
: E: Oh, that's the reason then. /Mm/ #
: A: [lahs tune] Right. #
: E: Just dry the back of your head cos #
: you don't want the back of your #
: neck wet do you? #
: [long pause as E helps A dry and #
: dress] #
: E: I've ordered a sandwich. I didn't #
: um, I didn't um- When I phoned #
: yesterday I didn't er ask your #
: husband specifically if I could #
: speak to you because I said to him, #
: þI presume A would like just a #
: sandwich againþ, an' he said. So #
: I've just ordered a nice wholemeal #
: ham sandwich for you for lunch #

today, okay?

A: Great, yes.

E: Cos your still having your main meal in the evening aren't you?

A: Well they moan at me if I don't eat. That's all ever-

E: Are you all done?

A: Yeah. S-sit down. I'll just s-sit on the

E: Sit on the chair, okay. [pulls chair over] But I mean, y'know, if ever you want to change it you just say.

A: Yeah.

E: Because there's always plenty of cooked.

A: I can have a sweet, can't I?

E: Yes. Yes, I've ordered sweet for you anyway.

A: D'you want me to sit th-there or there?

E: No you can sit there, A, now. We'll dry your bottom. Get you nice and dry. There that's it. Now I'll put some talcum powder on.

A: Ah! [long pause then lahs tune]

E: Your son lives at home does he? I presume he does, does he?

A: Er, a six- a sixteen and a half year old!

E: Yes. Yes, yes well. Yes, naturally Yes, yes, yes. Is he, um I mean, o-o-obviously he's still at school. What does he- does he know what he wants to do yet A?

A: Yes h-he wants to be a vet.

E: Oh, very good! A long training isn't it?

A: Seven years

E: It's longer than a doctor I believe.

A: Yep. My, er, my niece, who is er fifteen years old (he is not- months older really)

E: Yes, yes.

A: Wants to be a doctor.

E: Oh, right. So you- a doctor and a vet in the family ay? Very nice too! I think a doctorþs training is six years I think isn't it?

A: Yeah. Did I have those.

E: Did you- you have brought, I think, a change anþ, I don't know what is in here A.

A: But I- I-I

E: Those are they're clean anyway aren't they?

A: O-only. Only (7 syllables).

E: Yeah. Exactly, there's no- you don't need change those.

A: Well when I sorted it all yesterday- I- I don't know what people do with it all the washing.

E: Why?

A: Ah! I-it always stacks of washing in my house [laughs].

E: Really?

A: Y-yeah. [laughs] Yeah.

E: Mind you, You've got, what two men with shirts and things like that as well as all the towels and that. I

: mean, there's three of you isn't
: there in the house.
: A: Yes.
: E: And it's surprising how much
: washing there is. I mean my
: daughter, there's only her an' her
: husband, an' yet she seems to have
: the washing machine on very nearly
: every day as well.
: A: Oh well, I might soon get to the
: bottom.
: E: Right.
: A: We didn't make too much mess in
: here.
: E: We never do! We never do, do we?
: In any case it doesn't matter the
: floor is meant to be- to get wet an'
: what have you. Only one jumper
: today! You usually wear two don't
: don't you.
: A: Yeah well, I got that on there.
: E: Oh, you got that on top, yes. I
: like this. This is very nice. It's
: pretty. There we are, okay? You
: didn't wear tights did you? No you
: got socks.
: A: I've got (some horrible) tights.
: My Aunt, who comes down tomorrow,
: she won't (meet a man) without
: having her tights on.
: E: Why? You don't really need them
: under the trousers though, do you?
: A: She says they're warm.
: E: Well yes, I suppose so, but I mean
: if you- if you feel warm anyway then
: there's no need is there?
: A: [grunts as tries to put trousers on]
: [lahs a tune]
: E: There we are. Lovely.
: A: Yep.
: E: If you sit down again an' I'll help
: you on with your socks and shoes.
: That's it, okay? That's nice getting
: your toe nails trimmed, getting your
: feet sorted out isn't it?
: A: What I said to 'im um- þI'm
: dreading thisþ.
: E: Why?
: A: Huh my Nan made such a fuss when
: he did hers. Anyway huh
: E: Let's have the other one dry it.
: I'll dry it.
: A: I never ever knew what he was
: doing.
: E: Well you shouldn't do really. I
: mean there shouldn't be anything
: painful or uncomfortable about it.
: A: Oh, I dunno. That big toe of
: mine was a bit of a state.
: E: Yes it was, but I mean, a proper
: chiropodist should be able to do all
: that without causing you any
: discomfort.
: A: Yes. We had to get him out of the
: paper.
: E: Oh, did you?
: A: Um because
: E: Um was it local? Was it [name of
: town] or
: A: Yes. You see, er (can't think of
: the word) they said the clinic would

```
:   be about three months.                  #
: E: I know, this is the trouble. This      #
:   is       what, y'know, I think L [day   #
:   care leader] said to you before         #
:   didn't she?  You know it's such a       #
:   long waiting time                       #
: A: Yeah. Yep. Right.                      #
: E: So it's nice that you could get it     #
:   done.                                   #
: A: Yep.  The                              #
: E: I know it means that you've got to     #
:   pay to go private                       #
: A: Yes.                                   #
: E: of course but, I mean,                 #
:   unfortunately this is what happens      #
:   these days isn't it?                    #
: A: /Mm/ [lahs tune]                       #
: E: Well L- [day care leader] L will be    #
:   on her way      home now [from her      #
:   holiday], I expect, on the train.       #
: A: Yes.                                   #
: E: Hope she's had a nice time.            #
: A: Yeah.                                  #
: E: Right, that's that one, an' I'll       #
:   just do this one up.                    #
: A: [lahs tune] Th- that feels better      #
:   doesn't it?                             #
: E: Feels nice?                            #
: A: Yeah.                                  #
: E: There's nothing like a bath. I         #
:   prefer a bath to a shower. A shower     #
:   is useful if you're in a hurry isn't    #
:   it? It's handy in the summer,           #
:   actually, if you've just come in        #
:   from the garden, or something like      #
:   that an' you just want a quick          #
:   freshen up. But I still think a bath    #
:   is the nicest. I'll just get your       #
:   brush A. I'll just brush your hair.     #
: A: What hair? [laughs]                    #
: E: I think you'd better leave your wig    #
:   off until this is completely dry.       #
:   Don't put your wig back on while it     #
: A: Leave it (to put on what)              #
: E: Leave it until it's completely dry     #
:   before you put it on. All right?        #
: A: Yep.  Yes I will                       #
: E: Y'know, give your- your hair just      #
:   a   chance to breath a little bit       #
:   an'- 'cos the room's nice and warm      #
:   anyway. We can put it on before you     #
:   have lunch.                             #
: A: No, no!                                #
: E: There you are.                         #
: [A puts a jumper on]                      #
: A: Cor! This is hot.                      #
: E: D'you need it on?                      #
: A: Yes. [laughs]                          #
: E: Cos, y'know, it's quite warm on the    #
:   unit.                                   #
: A: There y'are huh.                       #
: E: Well hopefully we should all soon      #
:   be able to put some slightly cooler     #
:   clothes on. I don't think it's gonna    #
:   happen yet.                             #
: A: There is quite a lot of hair           #
:   there.                                  #
: E: Yes there is.                          #
: A: (5 syllables)                          #
: [long pause]                              #
: E: Thing is, you've got yer nice wig      #
```

that you can put on when you are going out anywhere special, if you feel you want it on anyway, haven't you. And as I said, it doesn't look like a wig. I've never seen such a good one. To be quite honest it's the best on that I- I've ever seen.

A: I should have had a ginger one!

E: Oh, A! [laughs] Would you have liked a ginger one?

A: G-ginger afro!

E: Oh! Right, well, that would have been fun wouldn't it! I dunno whether- what your husband might have thought about that though. D'you think he would have approved?

A: I dunno. I don't think he'd mind in the least what I'd do.

E: No, I'm sure he doesn't.

A: And my son a- and his mates too. (I s- I said) about an afro wig.

E: Oh, they suggested an afro wig, did they? Well that sounds typical actually, doesn't it?

A: [laughs]

E: Right, if I put that- I'll put that in your bag for you at the moment A, alright? I'll pop it in your- in there, that's it. There we are.

A: I'm supposed to wash it aren't I? As well?

E: Have you washed it? Is there- I think there's a special way of washing wigs isn't there? [they leave the bathroom]

**b)** Example of an interview transcript

Site C, 27th September 1996: Interview with a patient (Ek). Ek is 41 years old and has motor neurone disease. Amongst other physical effects, the condition has caused dysphagia. The researcher's difficulty in comprehending all that was said by the patient means that the transcript is somewhat incomplete. This is not typical of all the interviews. This transcript was selected for full presentation because of its relative brevity. The transcript has been entered into, and numbered by *the Ethnograph*.

```
: +visitors room

:

: AL: Generally about the hospice,  how
:   did you first hear about the
:   hospice?
: Ek: In my um motor neurone
:   association meeting we had Dy
:   [volunteer co-ordinator], an- a lady
:   from the [another day care] saying
:   what they do for day care patients
: AL: Yeah.
: Ek: [mumbled talk]
:   [telephone rings - AL picks up
:   phone, replaces receiver as noþone
:   there]
: Ek: I was quite pleased to hear that
:   there was somewhere else to go
: AL: /mm/ You said [name of other day
:   care] what's that?
: Ek: Another hospice near [name of
:   town]
: AL: Oh, I see. And they have day
:   care
: Ek: /mm/
: AL: as well?
: Ek: I think they do i- on most days o'
:      the week.
: AL: Right.
: Ek: but it's further to go there.
: AL: /mm mm/
: Ek: [very mumbled talk about other day
:   care] I don't know why they never
:   told me in the first place that
:   there was a nearer one
: AL: /mm/
: EK: then I could have enjoyed it for
:   longer! [laughs]
: AL: Yeah! So you initiated the
:   referral?
: Ek: Yeah, yeah.
: AL: How did you feel about being
:   referred?
: Ek: Yeah, I don't mind.
: AL: Um, the term þhospiceþ
: Ek: /mm/
: AL: I don't know whether that has a
:   specific meaning for you?
: Ek: Er, I think it's- it's where you
:   go to end your days, really.
: AL: /mm/
: Ek: (when you're too sick to stay
:      at home)
: AL: /mm/
: Ek: That's my view of what it was.
: AL: /mm/
```

Ek: erm (there's more too it)
AL: Yes? I me- how- in what way has that changed, your- your view?
Ek: Um, (there are other things) you can be- have respite care. Being helped [very mumbled speech]
AL: Yeah. In- during the course of your illness, even before, um you will have come in contact with other health care services, how does this hospice day care, or hospice service that you have experienced, compare with other services that you've had?
Ek: Um (I haven't really had any really)
AL: No?
Ek: Um [mumbled speech]
AL: Can I go on to day care? What were your initial reasons for coming into day care?
Ek: Um to get me out of the house some days to meet people. To give me something to do! [laughs]
AL:/mm mm/
Ek: (11 syllables)
AL: Have your reasons for coming Changed now that you've been here for a while.
Ek: No.
AL: What does day care offer you?
Ek: Well as I say I can have a chat with people. You know you're gonna get looked after. (3 syllables) You can m- make things. (You can have aromatherapy and hairdresser)
AL: Your initial hearing about the day care when Dy [volunteer co-ordinator] came to the meeting- Have your expectations- have your expectations been fulfilled?
Ek: M- more than what I thought, I think really.
AL: Yeah
Ek: [mumbled speech]
AL: Are there any aspects of day care that you particularly enjoy?
Ek: Um. I think it's good in therapy an' it gives me something else to think about.
AL: /mm mm/
Ek: [mumbled speech]
AL: Are there any aspects of day care that you haven't found enjoyable, that you've found are not your cup of tea?
Ek: [mumbled talk]
AL: So what do you tell others, perhaps your daughter, what do you tell her about day care?
Ek: They ask me what I've been doing, an' I tell them what I've made or painted. Sometimes they keep telling me they want more paintings.
AL: Really?
Ek: Yeah! [laughs]
AL: If you met someone who was in a very similar situation as yourself what would you encourage them to do?
Ek: (I'd recommend them to come to day care) [mumbled talk] I'd say pthe

: more the merrierþ, sort of thing!
: AL: Yeah, yeah. There's not that many
: of them.
: Ek: Yeah (5 syllables) on a Tuesday
: when I come there aren't any other
: (people)
: AL: That's right! I think they've got
: loads more room down there.
: Ek: Yeah!
: AL: What about your feelings about
: meeting other patients?
: Ek: Oh! I enjoy meeting people
: anyway.
: AL: /mm/
: Ek: [mumbled talk]
: AL: Yeah. Yeah. Are there any
: particular advantages of meeting day
: care patients?
: Ek: Well I think obviously we've all
: got some sort of illness so it helps
: you to see how they cope an'
: AL: /mm/
: Ek: (10 syllables)
: AL: Are there any disadvantages of
: meeting other day care patients?
: Ek: No, not that I can think of.
: AL: One thing that I've noticed while
: I've been here is that all the talk
: is very social, there's a lot of
: Ek: /mm/
: AL: laughs
: Ek: /mm/
: AL: and humour. What's your feelings
: about that- about that sort of
: style?
: Ek: Yeah. I like that really. I think
: that's me! [laughs]
: AL:[laughs]
: Ek: I can't always say the things I
: want to say. I can't get it out
: quick enough!
: AL:[laughs]
: Ek: I think with me you can- makes me
: laugh anyway! [laughs]
: AL:[laughs] Are there other times when
: you- you- you perhaps want a one-to-
: one talk? A more serious talk?
: Ek: /mm/ Well I think if you want that
: then you can go into the quiet room
: and have a chat.
: AL: /mm mm/
: EK: Um. Some of the staff think (12
: syllables)
: AL: Are there particular people that
: you feel you can talk to, if need
: be?
: Ek: I think I can talk to any of them
: really. Y'know A- A's [Day Care
: leader] the main one.
: AL: /mm/
: Ek: But I'm quite comfortable talking
: to anyone really.
: AL: Is there anything you donþt like
: about the um, sort of, general
: milieu of day care?
: Ek: Not really no.
: AL: It's very much favourable for
: you.
: Ek: Yeah. It all seems to go too
: quick!
: AL: Yeah.

: Ek: I go home feeling quiet tired but- #
: AL: huh #
: Ek: Yeah, I've got quite a few #
:   memories! #
: AL: Yeah.  D'you mind if I go on to #
:   the third #
: Ek: Yeah. #
: AL: theme about your experiences #
:   around your illness? #
: Ek: Yeah. #
: AL: Ho- how did you first find out, or #
:   first realise that there was #
:   something wrong? #
: Ek: hm it was about three years nine #
:   months ago. I used to work in the um #
: [mumbled talk] a couple of my fingers #
: couldn't reach the keys #
: AL: Oh, right. #
: Ek: An' there was a feeling like pins #
:   and needles, an' I woke up in the #
:   morning like I had a dead leg, an' #
:   things like that. #
: AL: /mm / #
: Ek: I never left it too long. I #
:   didn't like the way I felt, an' #
: AL:/mm/ #
: Ek: went to the GP but um he first #
:   thought it might be a trapped nerve #
:   in the elbow.  An' that was in the #
:   February [mumbled speech] an' then #
:   they took me for all the #
:   neurological tests, an' that was the #
:   following January #
: AL: /mm/ #
: Ek: It took a year to find out what it #
:       was. An' my worry at the time #
:   was- was it going to keep going. #
:   Like, would they be able to cure it? #
:   [mumbled speech] #
: AL: Did you have any ideas of your own #
:   of what it could be, in that year? #
: Ek: mm No. My, my only thought was #
:   maybe it was M.S., an' maybe #
: [mumbled speech](it was a shock) #
: AL: So when- how were you told? #
: Ek: I was told in the hospital, an' #
:   the consultant said he wanted my #
:   husband to be there, þI have the #
:   resultþ, so I thought, þthis is #
:   gonna be badþ news! [laughs] An' #
:   then (4 syllables) lumbar puncture. #
:   He come round an' asked me if I knew #
:   what it was an' I said þmaybe M.S.þ, #
:   he said þnoþ, he said (þthe cells #
:   are dying off in your spineþ) #
: AL: Pardon? #
: Ek: þThe cells are dying off in your #
:   spineþ. An' I said þOkay, what yer #
:   gonna do?þ, an' 'e said þnothingþ, #
:   (I sat on the bed, an' I thought, #
:   þAh! Oh, greatþ! #
: AL: So did he actually say "motor #
:   neurone disease"? #
: Ek: No. No. He told me there was #
:   nothing that could be done. An' I #
:   was sort of gob-smacked! [laughs] #
:   Then the (14 syllables) an' did I #
:   know what it was, I said þnot #
:   reallyþ, an' þe said, þwell (5 #
:   syllables)þ, an' how well did I know #
:   my GP, an' I said, þVery wellþ. He #

said, (þgood, go out and keep in touch with himþ) That's how it was left really. I did have my friend with me by that time 'cos my husband had run away (9 syllables)

AL: /mm/

Ek: an' 'e (16 syllables) okay! an' I said I gotta be!

AL: /mm mm/

Ek: (9 syllables)

AL: /mm/ What were your initial reactions and feelings?

Ek: Yeah. I was pretty shocked, um Not really knowing anything about it an' I thought I gotta find out what I can. An' then the consultant said, þbecause of yer age you might come through it. There's nothing medically that you can doþ, so I (5 syllables) turned to complementary therapy, see if they can help me.

AL: /mm/

Ek: I'm not gonna give up!

AL: /no/

Ek: You feel as though you (sort of say it's negative) (8 syllables) for motor neurone but (8 syllables) eh. Um, basically you take one day at a time, an' I (like) to think there's some worse than me [mumbled speech] through the motor neurone association. They're very supportive um [mumbled speech]

AL: How do you see your future?

Ek: I (sort of don't look too far ahead but) um [mumbled speech]

AL: You mentioned you found out lots through the motor neurone, is it þassociationþ?

Ek: Yeah.

AL: Would you have preferred to have more information at the beginning, or less information, or was it about right?

Ek: I think I would have liked it if the consultant had told me more.

AL: /mm/

Ek: But then, maybe they think, oh, they can't give you too much information, won't take it in.

AL: /mm/

Ek: You're feeling pretty shocked by then (for sure). But um (13 syllables)

AL: /mm/ How did you feel- if you could have (3 syllables), did you feel you wanted to know more or

Ek: Yeah. No. (I sort of faced it an' the next thing I knew e'd gone out again!) [laughs]

AL: [laughs]

Ek: Oh. If you know [mumbled speech]

AL: You mentioned that you didn't know- you hadn't really heard of motor neurone before like you had M.S. do you think that makes a difference? Having something that very few people have heard of let alone seen or?

Ek: I think it is difficult at times 'cos like people presume that I've

: either had a stroke or I've got M.S. An' you say þmotor neuroneþ an' they say þwha' on earth's that?þ (An' you have to go off an' explain i' all to them)
: AL:/mm/
: Ek: um (5 syllables) local information there's quite a few people with it so (12 syllables) they said it was only something that el- elderly people get but not young people. Um. [mumbled talk - about prognosis?]
: AL: How do you cope with that?
: Ek: hm as I say, I take one day at a time. (Yeah the only thing) I'm frightened of is when I choke on things.
: AL: Yeah.
: Ek: (4 syllables)
: AL: Yeah, I think that's happened here
: Ek: Yeah
: AL: a couple of times.
: Ek: Yeah
: AL: /mm/
: Ek: (6 syllables) like the water if it's too cold (8 syllables) an' also if I fall over
: AL: /mm/
: Ek: that's pretty frightening
: AL: /mm/
: Ek: (5 sylables)
: AL: /mm/ Have there been any particular episodes during your illness that you've found upsetting?
: Ek: Erm, I fell over an' cut my head open quite badly, an' that was just over a year ago.
: AL: /mm/
: Ek: An' I had to have five stitches in my head! It really shook my confidence.
: AL: /mm mm/
: Ek: An' after that I was frightened to let go of anything.
: AL: /mm/
: Ek: I dunno what it is. Noises make me jump [mumbled speech]. My mum was getting breakfast an' the smoke alarm went off [mumbled speech - describes a fall? with some laughter]
: AL: That's been a particularly bad episode for you. Are there any good times that you can remember?
: Ek: Um, only any time I spend with my grand children (4 syllables) but they forget, an' that's it. They don't know any different, sort of thing. My little grand daughter, she's (2 syllables), she tries to help me.
: AL: How old is she?
: Ek: She's near- nearly three.
: AL: three?
: Ek: /Mm/ When I started using the frame (5 syllables) she hadn't been walking long herself [mumbled speech]
: AL: I asked you this question about

day care, um if you knew of somebody in the same situation as you, perhaps at the very beginning, how would you hope that person is treated?

Ek: What in day care?

AL: Um, no, more generally. If you think back, perhaps the times y'know in that year trying to work out what was the matter an' then you found out. What would you hope people, in that situation now, would be experiencing?

Ek: Well I hope they get the information as quick as they can. But then, some people don't want the information, I think [mumbled speech]

AL: You said, again right at the very beginning, that the doctor said there was nothing that he could do

Ek: Yeah

AL: What treatments have you had in the past?

Ek: What- (mainly) complementary, um (4 syllables) aromatherapy

AL: /mm mm/

Ek: I've enquired about um acupuncture, but when they heard what it was they didn't want me to (start, there was nothing they could do) um. Um. Radionics. Um

AL: Radionics?

Ek: Yeah. Not quite sure how it works.

AL: I've never even heard of it!

Ek: No?

AL: [laughs] no.

Ek: There was something in the paper said it can help different people with different illnesses so I thought I'd try it, but (4 syllables) I've only written too them

AL: Right.

Ek: An' they sent me some tablets to try, an' he sent me a letter an' even though they've never met me it sort of listed how I was! [laughs] I was completely amazed, an' I think he must be psychic [laughs] because of um (I hope to meet him when) [mumbled speech]

AL: In what ways d'you hope to benefit?

Ek: [mumbled speech]

AL: D'you take any drugs at all?

Ek: Yeah. I- I have got painkillers um I try not to take every day (so that it works when I do take them) but [mumbled speech]

AL: Do you feel you have a good relationship with your GP?

Ek: My GP?

AL: Yeah.

Ek: [mumbled speech - community GP services?]

AL: How comfortable do you feel talking with different people? Are you able to talk about your illness and your feelings about it?

: Ek: Mainly, yeah. Yeah. Sometimes I #
: get a bit choked up but basically I #
: will talk about it #
: AL: Yeah. What about with your- you've #
: got two daughters haven't you? #
: Ek: Yeah #
: AL: Are you able to talk? #
: Ek: Not really. I mean initially when #
: I got (diagnosed) they wanted to #
: know what it was an' both of them [ #
: mumbled speech] I think they have a #
: bit more now but I think they find #
: very hard talk. #
: AL: /mm mm/ You mentioned your husband #
: earlier, but I haven't heard you #
: talk about him? #
: Ek: Oh! He left me, Yeah. #
: AL: Right. Is that since you had the #
: Diagnosis? #
: Ek: Um. Well I think he was on his #
: way out anyway. In fact the day he #
: left me at the hospital, he said he #
: was going away on business (7 #
: syllables). When 'e found out it was #
: serious he came back for about two #
: or three months (an' then he went #
: again, I haven't had much contact #
: since, even to see my daughters, #
: which I think is hard for them #
: especially at home because I think #
: she needs him [youngest daughters #
: name]) I never expected him to stay #
: just because I was ill. In some ways #
: I feel I'm better off without him #
: there. At least we've all got family #
: and friends (10 syllables) #
: AL: /mm/ #
: Ek: (6 syllables) [laughs] #
: AL: [laughs] How comfortable are you #
: talking to the staff in the hospice? #
: I think you've said about that! #
: EK: Yeah! #
: AL: What about other patients? Do you #
: talk about your illness experiences? #
: EK: Not a lot. I mean, I don't #
: think (5 syllables) Last week Pl [a #
: patient] (6 syllables) he said, #
: þwell, d'you mind me asking what it #
: isþ, an' I told him (10 syllables) #
: an' then we didn't discuss it any #
: more. But I say we've all got #
: something wrong but I think you come #
: here to forget that. #
: AL: /mm/ #
: Ek: Sort of be normal I suppose #
: really #
: AL: /mm mm/ Well I hope I haven't, by #
: talking about- I haven't made you feel #
: awful! #
: Ek:No, no! [laughs] #
: AL: [laughs] #
: [interview finishes] -#

## **APPENDIX 6:** Data filing codes in *the Ethnograph*

| **CODE** | **CONTENT** |
|---|---|
| AUTHUM | abbr. for AUTHORITATIVE HUMOUR – joking related to participants (lack of) authority |
| AWARE | abbr. for AWARENESS – any item that is linked to participants knowledge/perception of terminal prognosis of others or self |
| COARSHUM | abbr. for COARSE HUMOUR – jokes that could be judged as 'bad taste' |
| BANTER | explicit examples of conversational joking |
| BLCKHUM | abbr. for BLACK HUMOUR – jokes relating to trauma, tragedy and/or death |
| BODYHUM | abbr. for BODY HUMOUR – jokes relating to body functions and anatomy |
| BRIEF | abbr. for BRIEFING – staff briefing sessions |
| CLINSUR | abbr. for CLINICAL SURVEILLANCE – examples of the monitoring of patients physical condition |
| DCCON | abbr. for DAY CARE CONTEXT – physical and organisational features of the day care surroundings |
| DCDEV | abbr. for DAY CARE DEVELOPMENT – details regarding the emergence of day care service |
| DCETH | abbr. for DAY CARE ETHOS – features relating to the day care atmosphere and philosophy |
| DCOBJ | abbr. for DAY CARE OBJECTIVES – details referring to the aims of day care |
| DCREF | abbr. for DAY CARE REFERRAL – details of how/when people referred/selected/recruited to day care |
| DISHUM | abbr. for DISABILITY HUMOUR – humour relating to participants physical condition or 'patient' role |
| DOING | examples of (non-verbal) activities undertaken by participants and any references (implicit or explicit) to 'doing' things |
| GENHUM | abbr. for GENDER HUMOUR – jokes relating to gender/sex |
| GREET | abbr. for GREETINGS/GOODBYES exchanged |

| | |
|---|---|
| HOSPCON | abbr. for HOSPICE CONTEXT – physical and organisational aspects of the hospice |
| HOSPER | abbr. for HOSPICE PERCEPTIONS – any reference to beliefs, feelings, attitudes towards hospice philosophy, context and care |
| HOSPETH | abbr. for HOSPICE ETHOS – features relating to the atmosphere and philosophy of the hospice as a whole |
| ILLINFO | abbr. for ILLNESS INFORMATION – details concerning patients' illness |
| INTALK | abbr. for INTIMATE/SAD TALK – talk of a serious nature/style or concerning sensitive/emotive topics |
| JOKE | explicit joke telling with a beginning and an end |
| JOVETH | abbr. for JOVIAL ETHOS – general description of talk style |
| PERINFO | abbr. for PERSONAL INFORMATION – details disclosed by participants about themselves |
| POSTHNK | abbr. for POSITIVE THINKING – examples of participants trying to view themselves/their situation positively |
| PTDEATH | abbr. for PATIENT DEATH – any reference to the death of a hospice patient |
| PTPAS | abbr. for PATIENT PASSIVITY – instances where a patient behaves passively or is viewed passively |
| PTSUIT | abbr. for PATIENT SUITABILITY – references to appropriateness of patient for day care or *vice versa* |
| ROLEDIS | abbr. for ROLE DISTINCTION – events/actions defining role positions of participants |
| SETTLIN | abbr. for SETTLING IN – reflexive details and events relating to the researcher's role |
| SOCETH | abbr. for SOCIAL ETHOS - examples of social atmosphere |
| TALKC | abbr. for examples of talk about or by carer about his/her role |
| TALKPT | abbr. for TALK ABOUT PATIENTS – examples of when patients are talked about in general conversation |
| TEASE | abbr. for TEASING – jokes aimed at one or more participants |
| VOLUN | abbr. for VOLUNTEERING – any reference to why/how they do it |

# **APPENDIX 7**: Example of coded field notes from *the Ethnograph*

Field notes for the 30th July 1996 (site C) after coding, as presented by 'Ethnograph' (a software package designed to assist qualitative data analysis). Refer to appendix 6 for coding definitions.

```
    : EVENT SUMMARY: Briefing, coffee &          1
    :   chat, chair physio, art/craft            2
    :   activities, lunch, sleep/chat/hand       3
    :   care, chapel/chat/handcare, tea &        4
    :   cakes/handcare, home. PRESENT: PTS -     5
    :   My, H, D, E, MA, M, Pt. VOLS am - J,     6
    :   K, S, Lv. pm - S, Du, Ps (V red x        7
    :   handcare) STAFF - A, R, N, Mg.           8
#-SETTLIN
    :   Worth pointing out that today there      9  -#
    :   was no "welcome to Alison" on the       10   |
    :   white board of names.                   11  -#
    :
#-DCETH      #-DCOBJ      #-JOVETH
    : DOCUMENT: On the wall with day care       13  -#
    :   information in the reception area of    14   |
    :   the hospice is a poster advertising     15   |
    :   day care.  It is written in large       16   |
    :   cartoon style 'bubble' overlapping      17   |
    :   writing of all colours.  In the top     18   |
    :   right corner is a cartoon face of an    19   |
    :   elderly man (he is bald) with a         20   |
    :   startled, spaced out sort of            21   |
    :   expression.  Amongst the writing are    22   |
    :   coloured balloons.  The poster          23   |
    :   reads: " Have you considered            24   |
    :   toddling along to Day Care? [day        25   |
    :   care is written in larger letters]      26   |
    :   Laughter, friends, activities,          27   |
    :   outings. Ask for details - do           28   |
    :   it...now!                               29  -#
    :
#-BRIEF
    : EVENT: BRIEFING - summary: Lv, Me and     31  -#
    :   A talked about Ny and her               32   |
$-HOSPCON
    :   radiotherapy treatment, Lv made         33   |   -$
    :   coffee on request of A 'cos the         34   |    |
    :   catering staff were busy on 'the        35   |    |
    :   other side'. A talked about pts,        36   |    |
    :   general talk about weekends, J          37   |   -$
    :   bringing along a friend next week,      38   |
    :   asking if ok, talk turned to Lv's       39   |
    :   grandaughter and new zealand, travel    40   |
$-ILLINFO
    :   and driving rules of the road.  A       41   |   -$
    :   said that Ny's radiotherapy is          42   |    |
    :   palliative for relief of her pain       43   |    |
    :   because "NSAID's" and other drugs       44   |    |
    :   don't work for her.  "Dxt" has          45   |    |
    :   worked before for Ny in the relief      46   |    |
    :   of pain so it is hoped to do so         47   |    |
%-PTDEATH    %-AWARE
    :   again.  Lv and A said that Ny is not    48   |    |   -%
    :   ready to go (die) yet. Her husband      49   |    |    |
    :   seems to becoming round to it the       50   |    |    |
    :   thought of his wife's death. Lv         51   |    |    |
    :   gives an example of how she knows       52   |    |    |
    :   this - when Lv asked him how Ny was     53   |    |    |
    :   he replied with "Well she's still       54   |    |    |
    :   here". ( Lv is Ny's community           55   |    |    |
    :   volunteer and visits them regularly     56   |    |    |
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    :   and has done so for quite some        57    |    |    |
    :   time.) Lv said that Ny knows that     58    |    |    |
    :   her disease is terminal but she is    59    |    |    |
*-JOVETH     *-ROLEDIS
    :   not yet ready to die. A showed a      60    |   -$   -%   -*
    :   postcard sent to dc and for me to     61    |              |
    :   guess who from - didn't know - Pl.    62    |              |
    :   Called himself "Jock strapp" and      63    |              |
    :   wrote funny cryptic messages to       64    |              |
    :   individual male pts and made a joke   65    |              |
    :   about A keeping up the discipline.    66    |             -*
    :   Lv got coffees for all and A started  67    |
$-JOVETH
    :   briefing. May - "same as usual",      68    |   -$
%-DOING
    :   Harry - "fine", better nice to see    69    |    |   -%
    :   him being "productive" after his few  70    |    |    |
    :   weeks of not being able to do         71    |    |    |
    :   anything. Pl - on holiday "vis a vis  72    |    |   -%
    :   the postcard", Ny - away having       73    |    |
    :   radiotherapy. K groaned at this       74    |    |
    :   point and said what was the point of  75    |    |
    :   coming in then "we may as well all    76    |    |
    :   go home" to which A retorted          77    |    |
    :   authoritatively but jokingly, "now    78    |    |
    :   then K there's no need for that". D   79    |    |
    :   - back after IOW holiday, K said "Oh  80    |    |
    :   No!" and groaned even louder in an    81    |    |
    :   exaggerated way and made a comment    82    |    |
    :   about needing to keep her in order    83    |    |
    :   and A agreed saying that yes "the     84    |    |
    :   noise level will go up                85    |    |
    :   concurrently". E - the "official day  86    |    |
    :   care observer!" referring to E not    87    |    |
    :   interacting very much "she takes      88    |    |
    :   everything in". MA - don't know how   89    |    |
    :   she is 'cos not in last fri need to   90    |    |
    :   find out. M - enjoyed stay in         91    |    |
%-HOSPETH
    :   hospice but at home now. R agreed     92    |    |   -%
    :   that she had enjoyed herself.  A      93    |    |    |
    :   explained that M had not wanted to    94    |    |    |
    :   come in but once here had enjoyed it  95    |    |    |
*-CLINSUR
    :   tremendously. Pt - "insulin           96    |    |    |   -*
    :   controlled diabetic" who "will stuff  97    |    |   -%    |
    :   his snout into any box of             98    |    |         |
    :   chocolates" so need to watch and      99    |    |         |
    :   moderate his intake. A then said for  100   |   -$        -*
    :   J to do the art and Lv and S to do    101   |
    :   "the rest of the stuff in here" (ie   102   |
$-SOCETH
    :   the menus, table setting, drinks) A   103   |   -$
    :   signalled the end of proper briefing  104   |    |
    :   by asking generally about people's    105   |    |
    :   weekends.  J said she had had a nice  106   |    |
    :   one and then said that next week she  107   |    |
    :   has a friend staying and could she    108   |    |
    :   "bring her along". A said so and Lv   109   |    |
    :   said that she could bring in her      110   |    |
    :   "baby". She said that she has had     111   |    |
    :   the baby, her granddaughter with her  112   |    |
    :   for 3 months adding that she had her  113   |    |
    :   son and daughter in law staying too.  114   |    |
    :   A said that baby would be welcome.    115   |    |
    :   Lv then said that they had lived in   116   |    |
    :   new zealand for two years and talk    117   |    |
    :   turned to the country and travel and  118   |    |
    :   rules and etiquette of driving        119   |    |
%-ILLINFO
    :   differing in different countries. Lv  120   |   -$   -%
```

```
    :   and A talked about radio and           121   |          |
    :   chemotherapy A saying that what was    122   |          |
    :   given depended on the type of          123   |          |
    :   tumour, some being sensitive to        124   |          |
    :   radio and some being sensitive to      125   |          |
    :   chemo and some both. A's voice         126   |          |
    :   became softer and more                 127   |          |
    :   "professional" and serious as she      128   |          |
    :   talked about this with Lv.  I assume   129   |          |
    :   Lv asked A so it was a mini teaching   130   |          |
    :   session.                               131  -#         -%
    :
 #-INTALK
    : EVENT: COFFEE & CHAT -  Patients         133  -#
    :   arrived saying hello to one another.   134   |
    :   As usual the men Pt and H sat to the   135   |
    :   right and the women to the left in     136   |
    :   their 'usual' chairs. Talk was not     137   |
    :   as raucous as usual and a few people   138   |
    :   (including A) commented on this. A     139   |
    :   sat in the chair next to MA and        140   |
    :   talked 'closely' to her.  She sat      141   |
    :   forward in her chair facing MA,        142   |
    :   knees pointed towards MA. Her hands    143   |
    :   were clasped together in a relaxed     144   |
    :   fashion on the arm of the chair        145   |
    :   between herself and MA.  This was      146   |
    :   again some 'serious' talk.  A was      147   |
    :   asking how MA was, looking intently    148   |
    :   at her, using a soft voice, being      149   |
    :   affirmative (eg. "it's full of ups     150   |
    :   and downs") and empathising in her     151   |
    :   comments.  Asked about her pain. the   152   |
    :   rest of the people there talked        153   |
    :   amongst themselves as a group with     154   |
    :   some banter but quieter than usual.    155  -#
    :
 #-JOVETH
    : EVENT: CHAIR PHYSIO - A, R, S and Lv     157  -#
    :   joined in the exercises seated in      158   |
    :   the main circle of chairs although     159   |
    :   the vols sat on stools pulled in to    160   |
    :   form the circle (they were last to     161   |
    :   join group cos of duties).  As usual   162   |
    :   there was laughter but not raucous.    163   |
 $-BANTER
    :   N commented on how quiet it was. A     164   |   -$
    :   joked about seeing Lv's knickers       165   |    |
    :   during one leg exercise, and Lv        166   |    |
    :   retorted "why not they're very nice    167   |    |
    :   knickers!". There was a lot of         168   |   -$
    :   laughing at one another but even       169   |
    :   more encouragement and praise          170   |
    :   particularly from N. Sly comments      171   |
    :   were made by A about the time          172   |
    :   (referring to last fri when N was      173   |
    :   late - an example of A's joking        174   |
    :   authoritarianism and discipline. E     175   |
    :   stopped doing the exercise and it      176   |
    :   took a few minutes for N to realise,   177   |
    :   but when she did it went like this:    178   |
    :   N: "given up E?", E: "can't do it      179   |
    :   'cos of my shoulders - the             180   |
    :   arthritis", N (smiling): yes it is     181   |
    :   difficult for my arthritis too but     182   |
    :   it's dreadfully good for it too". N    183   |
 $-DOING
    :   then clasps E's hand and laughs.  N    184   |   -$
    :   asked A about the time and A said it   185   |    |
    :   was time to "get this lot working!"    186   |    |
    :   and so there was movement to the       187   |    |
```

```
    :   therapy room.                         188  -#  -$
    :
#-DOING
    : EVENT: ACTIVITIES - D and R in the      190  -#
    :   conservatory making a bird box (when  191   |
    :   hammering or anything noisy is made   192   |
    :   this is where it is done so as not    193   |
    :   to disturb the inpt unit). D had a    194   |
    :   bit of individual physio in the       195   |
    :   therapy room behind the curtains      196   |
    :   first. H, paper framed a painting in  197   |
    :   had done with the help of J, E        198   |
    :   carried on colouring in a line        199   |
    :   drawing of an eagle and then went on  200   |
    :   to do the same on a picture of        201   |
    :   flowers, MA carried on the cross      202   |
    :   stitch tray mat she started last      203   |
$-BANTER
    :   week, My, E and P watched K as he     204   |  -$
    :   showed how to marble paint paper.     205   |   |
    :   The three of them actually did        206   |   |
    :   nothing but watch despite K's joking  207   |   |
    :   attempts particularly with My to get  208   |   |
    :   them doing something.  The three of   209   |   |
    :   them wore plastic aprons to protect   210   |   |
    :   their clothing. K made reference to   211   |   |
    :   the three's lack of activity saying   212   |   |
    :   things like "Oh it's a hive of        213   |   |
    :   activity down here!" and carried on   214   |   |
    :   marbling the paper. At one point Jn   215   |  -$
    :   (chaplin) came in saying hello        216   |
    :   saying to E "hello friend" to E who   217   |
    :   greeted him. He asked Ma how she was  218   |
    :   and then sat next to My and asked     219   |
    :   how she was: "fine". My then asked    220   |
    :   him in return and he made light       221   |
    :   jokes about putting everything down   222   |
    :   to age that this is a safe thing to   223   |
$-BANTER
    :   do.  Jn asked E what she was doing    224   |  -$
    :   and she said she wasn't doing         225   |   |
    :   anything but watching and My agreed   226   |   |
    :   saying that she could "enjoy it [day  227   |   |
    :   care] more" that way.  Jn and My      228   |   |
    :   then joked about A wanting everyone   229   |   |
    :   to enjoy day care and My  added that  230   |   |
    :   if that was the case then they had    231   |   |
    :   better stop enjoying it! My referred  232   |   |
    :   to A as "Madam".  Jn left.  K         233   |   |
    :   distributed new badges he had made    234   |   |
    :   for most people yellow and black and  235   |   |
    :   more easily readable than the         236   |   |
    :   others.  He said that I had           237   |   |
    :   "inspired" him because everyone       238   |   |
    :   could read my name. There were some   239   |   |
    :   comments about rabies from K and My   240   |   |
    :   (I don't know where this came from)   241   |   |
    :   and A's tendency to bite.  A came in  242   |   |
    :   asking what was being said about her  243   |   |
    :   and when told she said she had a      244   |   |
    :   "rabies list". K said: "I thought     245   |   |
    :   you walked funny" and A went on to    246   |   |
    :   explain that she has a list of ten    247   |   |
    :   people whom she would bite if she     248   |   |
    :   had rabies.  She said it was good     249   |   |
    :   for her allowing her to keep in       250   |   |
    :   touch with herself but said it would  251   |   |
    :   be telling to tell anyone who was on  252   |   |
    :   the list. This was all said in t      253   |   |
    :   joking tone. During the session       254   |  -$
    :   there were several references made    255   |
```

```
     :   by both volunteers and pts about the    256   |
     :   pts "working" during the session.       257   |
     :   This was with humour and usually in     258   |
     :   relation to A and her joke              259   |
     :   authoritative position.  Mg on          260   |
     :   returning to the room and MA said       261   |
     :   after MA had made one such comment:     262   |
     :   "It's not meant to be work, it's        263   |
     :   meant to be a pleasure" in a serious    264   |
$-INTALK
     :   softly spoken tone.  During the         265  -#   -$
     :   session A came in and knelt next to     266         |
     :   MA and the two of them talked           267         |
     :   'closely' in lowered tones. They        268         |
     :   talked about MA's pain and analgesia    269         |
     :   (she's on a syringe driver). There      270         |
     :   was some discussion about MA taking     271         |
#-GENHUM
     :   oromorph top ups as well.  Whilst A     272  -#   -$
     :   was in the room K asked her to help     273   |
     :   Pt put on his new badge.  A said to     274   |
     :   Pt that she was going to "fumble        275   |
     :   underneath your apron" to which         276   |
     :   everyone laughed and A realising how    277   |
     :   she sounded burst out laughing too.     278   |
     :   After helping Pt A said to Pt that      279   |
     :   she had found nothing under his         280   |
     :   apron but his cardigan and Pt           281   |
     :   responded that there was a whole lot    282   |
     :   more under his cardigan! to which       283   |
     :   they both laughed. While activities     284  -#
     :   went on Lv took orders for aperitif     285
     :   drinks (from vols staff and pts) and    286
     :   distributed them amongst the group.     287
     :   S set the table for lunch before        288
     :   coming into the therapy room and        289
     :   joined in the back chat and banter      290
#-BANTER
     :   going on.  Many jokes were made         291  -#
     :   about K's new badge which could be      292   |
     :   misread to say "Yen" so there were      293   |
     :   jokes about 'who would yen for K?'      294   |
     :   to which there was silence and then     295   |
     :   everyone laughed at the lack of         296   |
     :   response, and A said: "I feel dirty     297   |
     :   even at the thought of it".  K          298   |
     :   turned to My jokingly commenting on     299   |
     :   the way he is treated and My said       300   |
     :   that she liked him to which A said      301   |
     :   to My: "I'm disappointed in you My".    302   |
     :   This was all typical banter of the      303   |
     :   therapy room communication this         304   |
     :   morning.                                305  -#
     :
#-ROLEDIS    #-SOCETH
     : EVENT: LUNCH - I escorted MA to the       307  -#
     :   table asking where she wanted to sit    308   |
     :   she said that she should not sit at     309   |
     :   the end of "head" of the table 'cos     310   |
     :   D sits there.  She sat next to this     311   |
     :   position and sure enough D came in      312   |
     :   and sat at the head.  All the           313   |
     :   patients sat of were seated on the      314   |
     :   down bar of the 'T' shape of the        315   |
     :   dining table arrangement. R, myself,    316   |
     :   Lv, Du, Ps (who arrived as soups        317   |
     :   were served having had a very quick     318   |
     :   briefing from A in the quiet room)      319   |
     :   sat on the top of the 'T'.  The         320   |
     :   patients sat first  and the rest of     321   |
     :   us sat were there were spaces.  R       322   |
```

```
   :  commented to me somewhat          323   |
   :  apologetically that "it is difficult  324   |
   :  to break the circle" referring to    325   |
   :  the positioning of the patients all  326   |
   :  together next to one another.  He    327   |
   :  added that sometimes vols and staff  328   |
   :  do sit with the pts.  S and J served 329  -#
   :  the meals Lv had sandwiches (made in 330
   :  the hospice, I had my own sandwiches 331
   :  as did Du and R had his usual        332
#-DCOBJ      #-DCETH
   :  vegetable pasties. MA, D and M       333  -#
   :  talked animatedly amongst themselves 334   |
   :  at length about the hospice and day  335   |
   :  care. First of all they all agreed   336   |
   :  that M looked much better MA         337   |
   :  remarked on her smile.  Ps on her    338   |
   :  arrival went to say hello and added  339   |
   :  that it was surprising how they all  340   |
   :  coped.  MA said that she first found 341   |
$-HOSPETH
   :  out about day care when she came to  342   |  -$
   :  stay (as an inpt).  D explained how  343   |   |
   :  she hadn't wanted to come to the     344   |   |
   :  hospice thinking it was "a prison    345   |   |
   :  with bars" but as soon as she came   346   |   |
   :  here she loved it and wished she's   347   |   |
%-DOING
   :  come earlier. MA said that her       348   |  -$   -%
   :  friend had commented on how busy she 349   |          |
   :  always seemed to be and MA said "it  350   |          |
   :  is down to this place" helping her   351   |          |
   :  to "make the most of everything that 352   |          |
$-PTSUIT
   :  you can". Ma said that she met a     353   |  -$   -%
   :  woman at the hospital who would love 354   |   |
   :  to come but didn't feel she could    355   |   |
   :  because she couldn't be sure she'd   356   |   |
%-AWARE
   :  be well enough. D responded that     357   |   |   -%
   :  'they encourage you to go along      358   |   |    |
   :  especially when you're down'. M      359   |   |    |
   :  added that it depended on what the   360   |   |    |
   :  woman was "suffering from"           361   |   |    |
   :  presumably referring to the hospice  362   |   |    |
   :  selection criteria. The three of     363   |  -$   -%
   :  them talked about what the hospice   364   |
   :  dc offers and how it has enhanced    365   |
   :  their lives: the chapel services,    366   |
   :  doing things, outings, the food, and 367   |
$-ROLEDIS
   :  the volunteers.  They all agreed     368   |  -$
   :  that everyone is kind hearted and MA 369   |   |
   :  talking about the volunteers said    370   |   |
   :  that although you'd expect them to   371   |   |
   :  be "La de da" they are extremely     372   |   |
   :  kindly.  She said they can't help    373   |   |
   :  being "La de da" but that they do    374   |   |
   :  much good. (presumably referring to  375   |   |
   :  the relatively well off volunteers   376   |   |
   :  to whose large houses and gardens dc 377   |   |
   :  visits.)                             378  -#  -$
   :
   : EVENT: PM CHAT/REST - Pt, My, M, and  380
   :  D had a rest in the quiet room while 381
   :  MA, E and H sat in sitting room. V   382
   :  the hand care lady arrived and       383
   :  manicured MA's hands. H watched and  384
   :  rested (closing eyes). E soaked her  385
#-DCDEV      $-VOLUN
   :  hands ready for a manicure. I talked 386  -#  -$
```

```
    :   with J who explained that she had       387   |    |
    :   started volunteer work after her        388   |    |
    :   husband, father and mother died in      389   |    |
    :   turn all for whom she was the carer.    390   |    |
    :   The red cross had trained her a bit     391   |    |
    :   and then the hospice had got in         392   |    |
    :   touch with them about needing           393   |    |
    :   volunteers when the SHARE was set up    394   |    |
    :   (Support, Help and Relief Extended)     395   |    |
    :   a local organisation designed to        396   |    |
    :   help people care for those in the       397   |    |
    :   community ? whether terminally ill      398   |    |
    :   or not. She did that for a while        399  -#    |
    :   before the dc was set up at headway     400        |
    :   and it went from there where she did    401        |
    :   community based voluntary work.  She    402        |
    :   said that many of the volunteers        403        |
    :   a patient in the hospital- she isn't    408        |
    :   technically on duty). Only MA           409       -$
    :   remained in the room when the others    410
    :   went to chapel/stayed resting in        411
    :   quiet room.  Du and Ps went to          412
#-BLCKHUM    $-JOVETH
    :   chapel too. Ma, A, V and S talked       413  -#   -$
    :   about the use of humour and how it      414   |    |
    :   helps but some people find it           415   |    |
    :   distasteful. S gave examples from       416   |    |
    :   own life where father had made a        417   |    |
    :   joke about preparing for her mothers    418   |    |
    :   death one night when asked what he      419   |    |
    :   was doing following his wife's          420   |    |
    :   request to get the doctor.  His wife    421   |    |
    :   (S's mother) was disgusted at his       422   |    |
    :   joke when she was told about it         423   |    |
%-DCOBJ       %-DCETH
    :   later. MA said that her husband has     424   |    |   -%
    :   a good sense of humour and that         425   |    |    |
    :   makes things easier.   She said that    426   |    |    |
    :   that's what dc is all about having      427   |    |    |
*-BODYHUM
    :   a laugh and companionship. A said       428  -#    |   -%   -*
    :   that her husband too had a sense of     429        |         |
    :   humour and recounted a story  about     430        |         |
    :   when she had sever back pain and        431        |         |
    :   thought that it was her kidneys. She    432        |         |
    :   asked her husband if he would give      433        |         |
    :   her one of his and he had asked her     434        |         |
    :   how much she was willing to pay for     435        |         |
    :   it.  S gave another example of          436        |         |
    :   blackish humour used by a male          437        |         |
    :   amputee she met in hospital when she    438        |         |
    :   was stuck in bed after having a back    439        |         |
    :   operation. Someone had gone by the      440        |         |
    :   door joking that he/she wouldn't        441        |         |
    :   shut the door (as if to imply that      442        |         |
    :   they would get up to no good and S      443        |         |
    :   said that this man had replied "No      444        |         |
    :   , I'll keep one foot firmly on the      445        |         |
#-BANTER
    :   floor!".  Mg came into room ann sat     446  -#    |        -*
    :   across from the other s eating a        447   |    |
%-BODYHUM
    :   sandwich. Mg commented to MA that       448   |    |   -%
    :   they would go and look in the store     449   |    |    |
    :   at three o'clock and A coughed          450   |    |    |
    :   asking MA jokingly if she had any       451   |    |    |
    :   respiratory problems because            452   |    |    |
    :   presumably there is a lot of dust in    453   |    |    |
    :   there. She said that when she went      454   |    |    |
    :   in there she had had to take all her    455   |    |    |
    :   inhalers afterwards and couldn't        456   |    |    |
```

```
:   stop coughing.  She then added that      457   |    |    |
:   with her weak bladder it was in fact     458   |    |    |
:   "wheeze, cough, wee, wheeze cough        459   |    |    |
:   wee", and everyone laughed. A added      460   |    |    |
:   that by the time she got home she        461   |    |    |
:   was "wringing". Mg spluttered on her     462   |    |    |
:   sandwich and groaned saying to A  to     463   |    |    |
:   spare the detail: "d'you mind, I'm       464   |    |    |
:   eating!".  S talked of another           465   |    |    |
:   person she knew who had fractured        466   |    |    |
:   ribs after falling off the toilet        467   |    |    |
:   and was embarrassed to tell anybody      468   |    |    |
:   how he did it.  Mg said that she         469   |    |    |
:   wouldn't tell anybody how she did it     470   |    |    |
:   and A said that she would tell           471   |    |    |
:   everybody in detail. Mg added that       472   |    |    |
:   she thought A would tell everyone in     473   |    |    |
:   graphic detail, the size, shape,         474   |    |    |
:   colour and the like. Laughter.           475   |    |    |
:   Everyone else returned from              476  -#   -$   -%
:   chapel/rest for tea. Du served the       477
:   cake she had baked and S served the      478
:   drinks. Jn joined in too. Everyone       479
:   sat around talking generally. S, Ps      480
:   and Du cleared away, Du helped E to      481
:   the toilet, V went round the women       482
:   giving handcare (to all except M who     483
:   said she'd wait til next week).          484
:   Drivers arrived at three patients        485
:   went home.                               486
```

**APPENDIX 8**: Example of ‘discursive analysis’

Analysis of the data output for the code “DOING” from the field notes for 30th July 1996, site C (full coded field notes for this date are in appendix7)

`SORT CODE: DOING` (examples of (non-verbal) activities undertaken by participants and any references (implicit or explicit) to ‘doing’ things)

```
%-DOING
     :   Harry - "fine", better nice to see         69  -%
     :   him being "productive" after his few       70   %
     :   weeks of not being able to do              71   %
     :   anything. Pl - on holiday "vis a vis       72  -%
```

PT's productivity viewed positively
Links with notion of art and craft as 'work'. Emphasis is on the patient doing rather than nurse/vol.

```
$-DOING
     :   then clasps E's hand and laughs.  N       184  -$
     :   asked A about the time and A said it      185   $
     :   was time to "get this lot working!"       186   $
     :   and so there was movement to the          187   $
     :   therapy room.                             188  -$
```

DCL refers to the 'work' of art and craft activities. Authoritative voice. Humour

```
#-DOING
     : EVENT: ACTIVITIES - D and R in the          190  -#
     :   conservatory making a bird box (when      191   #
     :   hammering or anything noisy is made       192   #
     :   this is where it is done so as not       193   #
     :   to disturb the inpt unit). D had a        194   #
     :   bit of individual physio in the           195   #
     :   therapy room behind the curtains          196   #
     :   first. H, paper framed a painting in      197   #
     :   had done with the help of J, E            198   #
     :   carried on colouring in a line            199   #
     :   drawing of an eagle and then went on      200   #
     :   to do the sam on a picture of             201   #
     :   flowers, MA carried on the cross          202   #
     :   stitch tray mat she started last          203   #
     :   week, My, E and P watched K as he         204   #
     :   showed how to marble paint paper.         205   #
     :   The three of them actually did            206   #
     :   nothing but watch despite K's joking      207   #
     :   attempts particularly with My to get      208   #
     :   them doing something.  The three of       209   #
     :   them wore plastic aprons to protect       210   #
     :   their clothing. K made reference to       211   #
     :   the three's lack of activity saying       212   #
     :   things like "Oh it's a hive of            213   #
     :   activity down here!" and carried on       214   #
     :   marbling the paper. At one point Jn       215   #
     :   (chaplin) came in saying hello            216   #
     :   saying to E "hello friend" to E who       217   #
     :   greeted him. He asked Ma how she was      218   #
     :   and then sat next to My and asked         219   #
     :   how she was: "fine". My then asked        220   #
     :   him in return and he made light           221   #
     :   jokes about putting everything down       222   #
     :   to age that this is a safe thing to       223   #
     :   do.  Jn asked E what she was doing        224   #
     :   and she said she wasn't doing             225   #
     :   anything but watching and My agreed       226   #
```

- eg. of woodwork activity

- egs. of other art and craft activities: picture framing, painting, sewing.

- Encouraging patients to do things

Humour used

- PT referred to as 'friend'

- PT returns enquiry

equality

- eg. of patient NOT doing something by CHOICE saying that she could "enjoy it [day care] more" that way. Jn and My then joked about A wanting everyone to enjoy day care and My added that if that was the case then they had better stop enjoying it! My referred to A as "Madam". Jn left. K distributed new badges he had made for most people yellow and black and more easily readable than the others. He said that I had "inspired" him because everyone could read my name. There were some comments about rabies from K and My (I don't know where this came from) and A's tendency to bite. A came in asking what was being said about her and when told she said she had a "rabies list". K said: "I thought you walked funny" and A went on to explain that she has a list of ten people whom she would bite if she had rabies. She said it was good for her allowing her to keep in touch with herself but said it would be telling to tell anyone who was on the list. This was all said in a joking tone. During the session there were several references made by both volunteers and pts about the pts "working" during the session. This was with humour and usually in relation to A and her joke authoritative position. Mg on returning to the room and MA said after MA had made one such comment: "It's not meant to be work, it's meant to be a pleasure" in a serious softly spoken tone. During the

- Humour relating to false antagonism towards DCL (doing the opposite to what she wants) 'madam' – mocking DCL's authority?

- (I copied theirs in the first place!)

- mocking DCL again

- eg of banter mocking DCL

- A humourous warning to those who don't 'tow the line'?

- art + craft = 'work'

- paradox: art + craft viewed as 'work' as well as 'pleasure'

%-DOING

come earlier. MA said that her friend had commented on how busy she always seemed to be and MA said "it is down to this place" helping her to "make the most of everything that you can". Ma said that she met a

- Keeping busy considered beneficial

- DC enables PTs to make the most of life.

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